

## AIDS ACTIVISM, COMMUNITIES AND DISAGREEMENTS

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### ABSTRACT

Using the AIDS Coalition to Unleash Power (ACT UP) as a case study, the author argues that this social movement organization is going through a diversification process as activists increasingly integrate the HIV/AIDS research establishment. Consensus about goals, beliefs and strategies is increasingly missing. However, instead of limiting the analysis to a case of "identity politics," typical of the new social movements, the author argues that some divisions among activists (especially those stemming from the definition of AIDS and how it should be researched) are actually helpful in better understanding the disease.

### INTRODUCTION

....proprietary interests and conflict of interest within and among universities, pharmaceutical companies and government research have crippled the fight against AIDS in ways that can hardly be characterized as science. Dogma has prevailed at the expense of lives: the cytopathic model of HIV directly killing T-cells and causing AIDS is accepted by many as necessary and sufficient. Only recently has the scope of investigation expanded somewhat. Still, rational therapies based on a comprehensive model of immune dysregulation, 12 years later, remain unavailable. (Carter 1993)

The quote above echoes the new form of activism that the New York City-based group AIDS Coalition to Unleash Power (ACT UP) began to exhibit in 1987. Using the media and direct action, the activist intent was to intervene into the science of HIV/AIDS, and unapologetically rip open the deficiencies of the research system. ACT UP became famous very quickly for its massive demonstrations, its controversial Needle Exchange Program, and condom distribution to public high school students. Its efforts have stretched from addressing the needs of persons living with the virus for social services and health care, HIV prevention in the public school system, to biomedical research.

The organization defines itself as "a group of non-partisan individuals united in anger and committed to direct action to end the AIDS crisis." It loosely follows Robert's Rules of Order, and abides by the principles of participatory democracy (ACT UP 1990c). With no president and no paid staff, the predominantly white middle class male members discuss AIDS-related "issues" in the many committees that have developed since the creation of ACT UP. Many of the "actions" are thought out and organized in "affinity-groups," spontaneous groups created by individuals

who wish to work on an "action-oriented" project. ACT UP raises its own money and does not receive any from the government.

Since 1991, members have experienced increased diversification and tension in their positions toward treatment issues at a time when they markedly integrated the AIDS establishment, achieving representation in major scientific committees. Oddly enough, this diversification process has led both to successes and failures with regard to treatment issues. Members registered a stunning victory when the Centers for Disease Control (CDC) finally accepted to expand the AIDS definition to include women's and injection drug users (IDUs)' opportunistic infections. They also experienced a weakening of their activist effort when crucial members of Treatment and Data (T&D), ACT UP's scientific committee, left to create their own "by-invitation-only" organization. The life of the organization has ever since followed a see-saw evolution, enjoying few significant successes, and facing equally significant failures. The present paper focuses on the cultural meaning of this diversification process.

### NOT ONE VOICE

ACT UP's diversification process has been analyzed as a typical case of "identity politics" or "cooptation," resulting from the sometimes conflicting, sometimes fragmented, constructions of treatment issues by activists based upon their various cultural and economic positionings (Burkett 1995; Gamson 1989). In some cases, activists were able to reconcile their differences, but in others, they refused because they saw these as simply irreconcilable. While some differences may have been due to the activists' socio-economic positionings, others stemmed from moral and epistemological grounds, that were hardly debatable and, instead, pointed to the multi-layered conceptualizations of HIV/AIDS. In

that sense, it is argued that while conflicts and clashes within ACT UP may have undermined the activists' work, they may have also enhanced our multiple understandings of the disease. Specifically, it is argued that whereas divisions over race, gender, and economic lines have indeniably undermined the organization, divisions over the "ontology" and "epistemology" of AIDS, that is its definition and the way it should be researched, have actually enhanced our multiple understandings of the disease. The present article therefore takes exception with the traditional view that new social movements, such as the one embodied by ACT UP, inevitably self-destruct through identity politics. Taking a more complex position, it argues instead that some divisions are destructive and others are not.

### FRAGMENTATION VERSUS MULTIPLE UNDERSTANDINGS

It is quite evident that ACT UP embodies a new social movement that can be characterized as the radical AIDS movement. Like the new social movements, its members can be described as primarily cultural, postmaterial, and postmodern moral crusaders (Habermas 1983; Offe 1985; Touraine 1985, 1990). Because many sociologists argue that the new social movements are not involved in the political and economic arenas, they are quick at determining that they often fall into the trap of "identity politics." Characteristically, ACT UP has been seen as following the same process of identity diversification, (Crimp 1990; Epstein 1991; Gamson 1989; Patton 1989; Watney, Carter 1989) even self-destruction (Burkett 1995). But few analyses have gone beyond this observation, and the legacy of the new social movement, of which ACT UP is the cultural manifestation warrants, it is argued, more interpretative work. In that regard, ACT UP as a new social movement is constructed as a multilayered entity, including not only various pre-existing identities, but also various "epistemological" and "ontological" belief systems as to how AIDS and its related research are constructed from a treatment perspective. Arguably, cultural analyst Donna Haraway (1991) offers a better theoretical framework to understand the legacy of the radical AIDS movement; beyond the traditional question of identity differentiation and division, she also takes on the debate of knowledge construction. Her concept of "situated knowledges" can be used to highlight how activists, even in

their innumerable disagreements, may actually enhance our understandings of the multilayered realities of HIV/AIDS. In sharp disagreement with the conventional view that science is unitary and aspires to universal truth, Haraway argues for knowledges that can only be plural and located in specific economic and cultural contexts. Knowledges may emanate from the center (position of those who have power) or the periphery (position of those who do not have power). What constitutes knowledge is not its origin, but the extent to which it has been put under "critical examination" (Haraway 1991). Because knowledges can only be situated, therefore contested, Haraway also champions a political epistemology, where people's positionings are in tension with the productive structurings that "force unequal translations and exchanges-material and semiotic-within the webs of knowledge and power" (Haraway 1991). The history of science, she asserts, can be described as the histories of technologies, themselves ways of life, social order, practices of visualizations. Objectivity is positioned and partialled rationality, and does not exclude engagement; no one can possibly be in all positionings at the same time, or even in one location entirely. Partial location does not equate relativism, for the latter denies stakes and responsibility and assumes transcendence of the ethical and political dimensions of situated knowledges. Instead, political and ethical terms ground, Haraway concludes, what constitutes valid and critical knowledges. While social movements have contributed to improving knowledges, some social interventions were not "liberatory," according to Haraway. However, like Bruno Latour, she supports lay individuals' involvement in scientific inquiry, because ultimately science is influenced by a whole array of actors including scientists, bureaucrats, elected officials and consumers themselves (Latour 1986, 1987; Latour, Woolgar 1979). This social constructivist perspective on science explains ACT UP's rapid successes and failures as the organization became directly involved "inside the arena of biomedical sciences," and challenged areas of knowledge thought to be the preserve of experts only.

Focusing upon the area of HIV/AIDS treatment and research, this paper intends to demystify the "universalistic notion of an activist community speaking with a single voice." Using Haraway's perspective, it will show how definitional contests in which activists have

engaged illustrate their various positions with regard to treatment issues, their ethical choices, their compromise, and also their irreversible schisms. Beyond the "destructiveness" of identity division, it is argued that ACT UP members' various discussions of treatment issues have also spotlighted multiple and useful understandings of HIV/AIDS.

### CULTURAL ANALYSIS

Different sources of information were used for this research. For three years (1990-1993), ethnographic observation and twenty-five semi-structured in-depth interviews were conducted at the Gay and Lesbian Community Services Center of New York City where ACT UP regularly meets, or at the activists' private homes. Each interview lasted about one hour, and activists were told that anonymity would be ensured as would their right to refuse answering certain questions, or to stop the interview at any time. Because of their heavy involvement in addressing issues related to HIV/AIDS-research, members of the Treatment and Data (T&D) committee, the Lesbian Caucus, and the Alternative and Holistic (A&H) committee were selected as research subjects in a non-probabilistic fashion. Ethnographic notes were taken during the general assembly meetings on Mondays, and during the meetings organized by activists working on treatment issues. Both methods, ethnography and interviews, specifically looked at the activists' socio-economic profiles, their constructions of HIV/AIDS treatment issues, particularly as they relate to "biomedical research," and their understandings of the conflicts that both "plagued" and "enriched" the organization. The main intent of the cultural analysis was to capture the various meanings that activists attached to "HIV/AIDS treatments," and the "actions," strategies, alliances and divisions prompted by these meanings (Foote White 1984; Vann Manneim 1988). The activists' archives, the access to which was granted by ACT UP, as well as the general AIDS-related scientific literature were additional sources of information enhancing the cultural analysis of this segment of the AIDS movement, providing illustrations of issues that were sources of division among activists.

### ONE VOICE, ONE COMMUNITY: A STRATEGIC NECESSITY

Noteworthy is that differences within the group existed since its creation in 1987. A

coalition, ACT UP was very well aware of these differences, but because of the sense of emergency prompted by the epidemic, activists "strategically" agreed to focus upon common goals and tactics, as illustrated by one member: "when you do coalition work, you learn to make a lot of compromises." This focus led them to understand that confronting the HIV/AIDS research establishment meant confronting a whole system involving drug companies and federal bureaucracies. With the "global" outlook, and the focus upon common goals and tactics, ACT UP registered many successes: its first massive demonstration was organized in 1987 against Burroughs-Wellcome, the manufacturer of Azidovudine (AZT), the price of which originally ran as high as \$12,000 for a yearly supply. Despite unprecedented federal support, this company and others were reaping unethical profits, activists complained. Ultimately giving in to the activist pressure, Burroughs-Wellcom lowered its price by 20 percent (Hilts 1989).

In 1989, activists "shut down" the Food and Drug Administration (FDA), castigating the federal agency for slowing down the research process. Requiring very stringent procedures in the midst of an epidemic, FDA regulations were "murderous," activists claimed, and drug testing procedures needed to be streamlined (ACT UP 1989a). Often cited by the activists was the case of DHPG, a drug which is used to treat blindness-causing cytomegalovirus, an AIDS-related opportunistic infection common among persons living with the virus. As early as 1988 doctors knew from clinical observation that the drug was both safe and effective. Yet the FDA still required that a double-blind placebo-controlled experiment be conducted, causing an uproar in the HIV/AIDS community. This decision led to massive demonstrations, and the subsequent expedited FDA approval of the drug (ACT UP 1990c). Since then activists have been part of all the decision processes leading to drug approval.

Much HIV/AIDS therapeutic research is conducted by the federal research system called AIDS Clinical Trial Groups (ACTGs), composed of AIDS Clinical Trial Units (ACTUs) disseminated throughout the United States. After identifying the ACTGs' principal investigators (PIs) responsible for designing clinical trials, activists concluded that interlocking between drug companies and government hampered research creativity (ACT UP 1990a).

They discovered that many PIs working for the federal government had also contracted with private pharmaceutical companies under the veil of "consultative arrangements" (ACT UP 1990a). One activist deplored that: "The ACTGs system created as an alternative to the private system had actually become an integral part of it" (ACT UP 1990a). While this dual function was constructed by the activists as "conflict of interest," it was viewed by the researchers as a way to enhance communication between federal and private research (ACT UP 1990a). Arguing that this dual function granted federal researchers too much influence over the research agenda, activists often cited the undue focus upon retrovirals such as AZT. Meanwhile, people living with the virus were dying of opportunistic infections, which were hardly researched. Activists organized in 1990 a massive demonstration at the National Institutes of Health to denounce "conflict of interest" and the lack of research on opportunistic infections (ACT UP 1990a). Even though private consultation remained a common practice among federal researchers, more attention was subsequently devoted to opportunistic infections.

Angered by the exclusion of women's and drug users' opportunistic infections from the official definition of AIDS, ACT UP members flew to Atlanta in 1990, and "besieged" the Centers for Disease Control (CDC) (ACT UP 1989c, 1990b). Giving in to three-and-a-half years of arduous activist campaigning, the CDC finally expanded its definition to include some of these opportunistic infections (CDC 1993). Additionally, upon a legal suit launched by a lawyer, who was also an ACT UP member, the Social Security Administration finally agreed to change its definition of disability in the case of HIV/AIDS and open eligibility to many women living with the virus. Yet while enjoying all these successes and achieving representation in major governmental and pharmaceutical committees, ACT UP seemed to be facing internal ideological differentiation and dissension upon which the analysis of the present study centers.

#### **ACTIVISTS: NOT ONE COMMUNITY ANYMORE**

Just as activists were reaping the benefits of their continued activism, they began to experience increased dissension within the organization. Women became more vocal about their differences with men in terms of

critiquing conventional science. People of color, too, started to complain about incidents of racism in the organization. The diversity of theories to explain HIV/AIDS, and their incompatibility, also became increasingly obvious. In line with Haraway's (1991) concept of "situated knowledges," an important reason explaining ideological differences and increased diversification within ACT UP is its historical origin. ACT UP can be considered as a confluence of social movements including members from the pre-existing AIDS movement, the gay and lesbian movement (ACT UP 1989b), the feminist-health movement (ACT UP 1989c), and the alternative and holistic movement (ACT UP 1989d). All of these displayed commonalities, but sharp differences as well. For example, many members of the pre-existing AIDS movement were exclusively interested in "getting drugs into people's bodies" (ACT UP 1990c), while others were promoting alternative and holistic treatments. These differences were inextricably associated with the experience of each activist in her/his respective movement. Women, a significant number of whom had been part of, or informed by, the feminist-health movement, were extremely critical of the medical establishment. They criticized the "male bias" prevailing within clinical research, especially the historical exclusion of women from clinical trials. Often times they would cite historical examples of women being used as "guinea pig" for a "male-dominated" science (ACT UP 1989c): "If we do not take research into our hands, the Dalkon Shield experience may come back to haunt us!" exclaimed an activist, commenting upon the long mistreatment of women in biomedical research during a general assembly meeting. People of color in turn were not only concerned about clinical trial designs, but also about their access by disenfranchised populations lacking economic resources and overwhelmed by family responsibilities. On a regular basis, activists of African descent would remind the membership that AIDS was "just another problem decimating communities of color". "The white boys are going to find a cure. So what? you think that people of color will be able to afford the treatment?". All these concerns were tightly associated with ACT UP members' personal positionings in relation to the power structures, of which the medical establishment was, in the eyes of many activists, a clear reflection (ACT UP 1990c).

In the early days of the organization, the activists' "enemy" seemed to be similar for all members, until they started to gain community representation in the major scientific committees. These included virology and immunology committees that make the most consequential decisions regarding HIV/AIDS research; Institutional Review Boards (IRBs) that set ethical standards for research protocols; research bureaucracies such as the National Institutes of Health (NIH) where activists have gained representation through Community Constituency Groups (CCG), and finally drug companies where activists have achieved representation through Community Advisory Boards (ACT UP 1990c). While activists were making their entrance within the biomedical establishment, issues related to representation, until then kept in the dark, started to become more apparent; differences that were only debated from within ACT UP began to be brought to light. Activists' goals were no longer the same, and in the "activist" research perspective, substantive, methodological and strategic differences started to emerge with increased sharpness.

#### Substantive Differences

With regard to substantive issues, Haraway's (1991) perspective is helpful in that differences can be traced back both to people's positionings relative to the economic, cultural and research power structures as well as their individual choices. A significant number of members believed in the use of medicinal drugs, and followed their "career" (study the drug) very closely. In fact, the first committee created to address research questions was called "Treatment and Data" (T&D), the members of which followed almost exclusively biomedical research conducted by pharmaceutical companies and the federal government.

Fewer individuals in ACT UP believed in alternative and holistic treatments. These involved use of naturally occurring substances, the outcome of which could only be measured, activists asserted, from combined interaction between "mind, spirit and body" (ACT UP 1989d). At first, demonstrations were primarily organized to obtain medical treatments, but as activists were being integrated into the decision-making process, differences between the two "schools" became increasingly clearer; proponents of each school were progressively acting as adversarial competitors. Conventional science activists argued that:

members of the Holistic and Alternative Committee do not understand that there is not such thing as a totally innocuous treatment; that all treatments entail some level of toxicity.

Holistic activists displayed the same sarcasm through their regular criticisms of T&D members:

Even if members of T&D are interested in research in immunology, their ultimate purpose is to find a 'magic bullet' for each opportunistic infections. They miss the point.

Interestingly enough, both types of ACT UP members had made inroads in the federal bureaucracy: conventional treatment proponents had achieved representation within official scientific committees, successfully pressuring for more research on opportunistic infections; in turn, alternative and holistic proponents had been successful at pressuring the federal government for more research on "unconventional" treatments, a struggle that contributed to the creation in 1991 of an Office of Alternative Medicine at the National Institutes of Health.

The quest for a bridge between the two paradigms led a number of activists to select a communicative approach. Words such as "complementary" therapies were frequently being used. Most significantly, the fairly recently expanded research in immunology was also a factor contributing to the rapprochement between activists. Dissensions remained prevalent, however, because many activists lacked the ability to self-criticize, whereas only a few were able to open their "partial positionings" to other perspectives. Rather than stimulating creative discussions made up of partial rationalities and yielding "situated knowledges," the organization was increasingly plagued with emotional eruptions and was constantly pressured by influential members to "win over" the rest of the membership to their positionings (Wolfe 1992).

The most consequential division, however, stemmed from a disagreement about a clinical trial—076—between many T&D members (most of them were white middle class males) and most women in ACT UP. The purpose of 076, the first trial on women, was to study the effect of AZT on perinatal transmission. Most of the women enrolled in the study were African-American. Some ACT UP members, men and women, disagreed with

the fact that 076 should focus on the fetus and not the woman, when a study had already revealed that AZT could be carcinogenic to women. In March of 1991, the dissenting activists flew to Washington and attended the 076 investigators' meeting. There, they were faced with attacks of racism for allowing themselves to speak on behalf of a community of which they were not members. Back to New York City, the same attacks awaited them. Not only was race used against them, but their serostatus as well:

Seronegative ACT UP women were presuming to tell HIV infected women of color what to do. While the CCG (Community Constituency Group) thereupon took up the issues around 076 and tried to change the trial, the factional disruption impaired ACT UP's credibility and destroyed the morale of many treatment activists for a long time to come. (Harrington 1992)

In their response, the dissenting activists questioned the "ontological" and "epistemological" superiority bestowed upon seropositive individuals, and urged the opposition to be more inclusive and open to dialogue:

The point is that not all people with HIV agree on these or other issues. That's why ACT UP was called a coalition when it was formed by people from several different AIDS and lesbian and gay organizations who could only agree on working together to end the AIDS crisis. A coalition can't work if we don't admit that in every category used to describe us and that we use to describe ourselves (HIV+, HIV-, women, men, Afro-American, Latino/a, Native American, Asian Pacific Islander, white, gay, lesbian, straight, and so on) people within those categories do not always agree with each other. To infer that one particular committee or working group in ACT UP takes its direction from people with HIV while all others don't is simply untrue. And we have to find a way to have discussions about issues precisely because it's untrue, rather than to reify any one point of view as representative (or unrepresentative) of all HIV+ people, all HIV+AIDS activists, or all HIV- AIDS activists in ACT UP NY or other ACT UPs. (Wolfe 1992)

The call for dialogue was never heeded, and these "identity" divisions led many T&D members to leave the organization. ACT UP was for the first time facing the various layers of divisions constitutive of its membership. Some

of these divisions were based upon gender, race, class, and sero-status; others were based upon "ontological" and "epistemological" differences, or the way HIV/AIDS is constructed and should be researched. The first type of divisions could have been eliminated through critical reexamination, an endeavor in which many activists failed to engage, confirming Haraway's (1991) notion that "subjugated individuals" do not necessarily question their "partialled rationalities." The second type of divisions was harder to resolve as it addressed the various ways of conceptualizing and researching the disease, an issue that modern science has yet to finalize.

### Methodological Disagreements

Methodologically, what caused most discussion among activists was probably the debate over double-blind placebo-controlled experiments. Very important because it brought forward issues of ethics and personal responsibility in clinical trial designs, this debate was almost prophesied by Haraway's (1991) general discussion about science and objectivity. Two strains of thought prevailed in ACT UP. Some members tended to adopt the view that the scientific validity of double-blind placebo-controlled experiments should be "rehabilitated" in the HIV/AIDS community. They claimed that for too long ACT UP had hastily dismissed the significance of these experimental designs. In the case of anti-retroviral drugs such as AZT, ddI or ddC, and the protease inhibitors, important questions had been left unanswered. For example, when should people living with the virus take these drugs? in what amount? in what combinations? These activists argued that in some cases use of a placebo, which can be an active placebo or a standard therapy, was indeed the only way one would know the answer to these questions.

More grounded on historical and moral principles, the other camp of ACT UP members argued that even with double-blind placebo-controlled experiments, "you will never know how a drug works on your body" (ACT UP 1989c). As long as safety was demonstrated, they asserted, the decision to take the drug belonged both to the individuals and their doctors. Additionally, they argued on moral grounds that: "it is no one's right to prevent someone from taking a non-studied drug, if the person understands the risk incurred by such a personal venture". The placebo proponents and the moral/historical proponents brought

into relief the social constructivist character of biomedical research wherein choice, moral judgments, and even power seemed to be unavoidably associated. Even though the ultimate power of biomedical researchers to set research parameters had been tampered upon activists pressure, power *per se* had clearly not been eliminated. Major discussions arose as to which activist perspective would be advanced by ACT UP in terms of the organization's position *vis-à-vis* clinical trial designs. The two sides were almost incompatible, since double-blind placebo controlled experiments mandated that individuals not have the power to choose what "goes into their bodies," while the historical/moral perspective implied that individuals should be granted freedom to use whatever drug had clinically shown to be safe. These methodological differences existed among holistic activists themselves. Some of them believed that "holistic and alternative treatments" were beyond the scientific methods, in fact their efficacy could not be adequately proven by use of placebo research designs: "The very purpose of science is to break down reality, when holism is about continuity and harmony," a holistic activist asserted. Others believed that these treatments should not be immune to scientific scrutiny, as another member explained: "if a conventional treatment works, prove it; if an unconventional treatment works, prove it."

In the meantime, methodological differences among activists were gaining increased visibility in the media. While some activists attempted to think up a compromise between the two views, general discussions that should have yielded "situated, responsible and ethical knowledges" instead often deteriorated into manipulative exchanges to influence ACT UP policy recommendations. Committees that should have focused on different areas of research, also became "factions," smearing other activists' work: "scientifically" oriented members would often joke at "holistic" activists, and vice versa. However, methodological differences among activists never reached the level of destructiveness produced by differences in terms of gender, class, race and sero-status. Differences in the way activists constructed HIV/AIDS never led to a schism in the organization. The reason for this is quite evident as methodological differences appear to be inherent in the fact that the reality of HIV/AIDS and how it should be researched have not yet been definitively elucidated by

modern medicine. In that regard, methodological and substantive differences among activists are more enlightening about the reality of HIV/AIDS than actual sources of destruction for ACT UP.

### Strategic Differences

Tied into substantive and methodological differences were the activists' strategic disagreements. As they achieved their original goal—inclusion in the decision-making process—they almost simultaneously found it increasingly difficult to garner consensus about questions of strategy. Also compounding strategic difficulties, and creating many dissensions within ACT UP, was the lack of consensus about what members defined as the "AIDS crisis." Disagreements over strategy arose further when ACT UP members experienced ever-increasing difficulty in defining "AIDS activism." By 1991, differences between "treatment activists" and "social activists" clearly emerged: the former argued that AIDS activism was to be about the virus and how to "restructure the National Institutes of Health" to speed up the research process, while the latter claimed that the "AIDS crisis" could not be disentangled from the larger socio-economic crisis that plagued society, involving classism, racism, sexism and homophobia. The former's position is well articulated in one member's letter sent to the ACT UP membership. Expressing annoyance at the view that AIDS activism should be about anything else but the virus, he stated:

Yet no crisis has ever been like the AIDS crisis.

Thus, while we can and have learned much from previous movements, there is much we have had to invent for ourselves.

Our tactics, new methods, lacked the ideological "purity" demanded of "the movement." ...I thought the movement I joined four years ago was devoted to lengthening and ultimately saving the lives of people with HIV or AIDS. Had I known that some in ACT UP felt it was rather merely vague aspirations towards impossible Utopias, I might have devoted my energies elsewhere. I was not then, nor am I now, interested in leaving a noble, frustrated legacy erected over a pile of our corpses so that lifelong movement parasites can move on to the next issues. (Harrington 1992)

By 1990, several T&D members had already received personal invitations by the Director of

Federal AIDS Research, a gesture which angered many in ACT UP. Acrimonious exchanges were further exacerbated when women in ACT UP requested a moratorium on all meetings with governmental officials who had refused to include more women in clinical trials and create woman-specific research designs. Concerned about "survival time," men sent the membership a letter, indicating their categorical opposition to this moratorium and stressing once again the division between seronegative and seropositive individuals:

Just as seronegative activists had presumed to tell advocates of seropositive women of color how to think and act on 076, so they now presumed to tell ACT UP treatment activists—many of whom are actually living with HIV—how to work to save our own lives. (Harrington 1992)

As a result, some T&D members kept on having dinners with AIDS bureaucrats, intensifying the division within ACT UP. Interminable and angry discussions between the two groups led to a major schism, causing members from the Treatment and Data (T&D) committee of ACT UP to leave the organization and create their own organization, "Treatment Activist Group" (TAG), the strategic orientation of which is well expressed in the following statement:

We want a family atmosphere, and a team effort. No personality, political war. Everybody must feel part of a team. We do not allow saboteurs or hot heads. We had people attack us from behind, or impose their "social activism," with their formula. We have abandoned the politically correct form of activism. We just want to get things done.

Throughout the country, the various ACT UP chapters were experiencing similar tensions between "treatment activism" and "social activism": in San Francisco, T&D left ACT UP/ San Francisco to create a treatment-focused organization, ACT UP Golden Gate; in Chicago and Washington D.C., AIDS activists experienced drastic changes too. Illustrating Haraway's (1991) notion of contested reality, this split was certainly a test to ACT UP members' ability to think critically about their "positionings". In accepting one million dollars from Burroughs-Wellcome, (one of the activists' fiercest former enemies), TAG heralded a new form of activism, incensing many ACT UP members. By 1994, TAG members had

achieved representation in the executive board of the ACTGs with full voting power on a \$250,000 research budget. They would also meet on a regular basis with officials from pharmaceutical companies, Congress and the FDA.

Difficulties in reaching consensus regarding ACT UP's strategy was also reflected in the many hurdles that some ACT UP members had to overcome when promoting one of their latest initiatives, the Barbara McClintock Project or the AIDS Cure Act (ACT UP 1993). The Barbara McClintock Project was a proposed legislation written by some ACT UP members with the intent of drastically changing the structure of HIV/AIDS research in the United States. In particular, activists hoped that the AIDS Cure Act, if passed, would remove political and economic contingencies from the research arena. The AIDS Cure Act was named after Barbara McClintock to honor the courage of a woman researcher who resisted the conventional research paradigm and won the Nobel Prize for her work on DNA (ACT UP 1993). Many other ACT UP members felt challenged in their perspective by the multiparadigmatic approach promoted by the AIDS Cure Act, which ultimately did not bring the expected consensus, even from within the activist community. Some activists, prominent among whom were TAG members, thought that the AIDS Cure Act was too "unrealistic," and that AIDS activists should be working at the sides of researchers, promoting change from inside the bureaucracies. Negotiations between activists are currently in process while the AIDS Cure Act has been introduced in Congress in 1994. In turn, the same year, TAG members focused upon change within the AIDS bureaucracy. They accepted the appointment of one of its members by Bill Clinton to be part of the National Task Force on AIDS Drug Development; they also worked very closely with Congress politicians in order to "restructure the NIH." Drastically reversing their original demands, TAG members have attacked the process of accelerated approval, for which many of them had been previously fighting. Adding to the fury of ACT UP members, TAG has defended the pharmaceutical attempts to end the NIH's requirements that companies charge a "fair price" for drugs developed with the collaboration of federal scientists, arguing that profit was the "best way to entice drug companies into researching chemical components." Clearly, strategic differences

have never been so significant and consequential for the radical AIDS movement. More than internal infighting within ACT UP, the institutionalization of TAG members has the effect of weakening the activist effort by multiplying and "blurring" the enemies. ACT UP members' targets are not only the "government" or the "drug companies" anymore, but also other AIDS activists.

## CONCLUSION

While activists have achieved increased representation in the federal and corporate bureaucracies, they also have experienced increased diversification, even division, among themselves. Substantive differences could be felt between T&D members and women who were concerned about female inclusion in clinical trials, and more generally about how women are affected by the "AIDS crisis." Substantive differences could also be felt between "scientifically" oriented activists and "holistic" activists, who demanded that more "unconventional" treatments be researched. Differences also emerged as to whether seropositive individuals were "ontologically" and "epistemologically" superior with regard to HIV/AIDS because of their health status. Methodologically differences were experienced between "traditional science" activists and those who were critical of it. Among the latter were many women who thought that when a drug had been clinically shown to be safe, whether or not to take a drug was an individual question. Similarly, some holistic activists thought that conventional scientific methodologies could not be applied to "unconventional" treatments. Strategically, differences emerged when people of color complained about racism in ACT UP and the indifference of white middle class activists to the question of access to HIV/AIDS treatments by disenfranchised communities. Strategic differences were probably most consequential when a group of activists decided to leave ACT UP to create their "very selective" organization. Working from within or without the government (or both) was a crucially divisive question that lethally undermined the organization, many activists thought.

Even though some of these differences could have been bridged through critical examination (Haraway 1991) of how the AIDS crisis affects differently various groups, other differences were purely ontological and epistemological, making it very difficult for ACT UP

to find even a "strategically" unifying answer: the opposition between holistic and scientific activists, for example, narrowed down but never disappeared. Meanwhile, both types of activists made inroads within the federal bureaucracies, as a large body of research in immunology militated for a rapprochement between the two paradigms. So far, however, neither paradigm has prevailed, confirming that the conflicts that ACT UP faces may actually have no solutions, and instead reflect the various ways HIV/AIDS can be constructed. In that sense, while ACT UP as a social movement has to a large extent suffered from the destructiveness of "identity politics," it still enhances our multiple understandings of the disease, particularly through its internal ontological and epistemological discords over HIV/AIDS treatments.

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