Act Up, Fight Back, Fight AIDS! The legacy of ACT UP’s policies and actions from 1987-1994

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Abstract: The AIDS Coalition to Unleash Power (ACT UP) was founded in 1987 after a speech by Larry Kramer implored people to address the widespread destruction and deaths caused by HIV/AIDS. Since its founding, ACT UP has worked to improve the public’s awareness of the disease and to push for legislation that not only protected People With AIDS (PWAs), but also improved their access to medications and treatments. The way in which ACT UP achieved these goals, however, has provided a framework for other marginalized groups to make a similar impact. Some of the tools ACT UP used include: zaps, political theater and politicized art, transformation of emotion into enraged action, and laying the framework for a government-run and –funded project to fight HIV/AIDS. ACT UP’s methods forced groups to pay attention to PWA demands and address an issue that was often taboo or politically dangerous. ACT UP’s influence continues to be felt today among groups struggling to get their message out and engage the public on their issue.

Nathan H. Madson

I am someone with AIDS and I want to live by any means necessary. I am not dying: I am being murdered. Just as surely as if my body was being tossed into a gas chamber, I am being sold down the river by people within this community who claim to be helping people with AIDS.
Hang your heads in shame while I point my finger at you.

We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasional “patients,” a term which implies passivity, helplessness, and dependence upon the care of others. We are “People with AIDS.”

On June 5, 1981, the Centers for Disease Control and Prevention (CDC) announced an odd cluster of Pneumocystis pneumonia (PCP) in five gay men from Los Angeles, marking the start of the global AIDS epidemic. The earliest reports of Acquired Immune Deficiency

1 I would like to thank Michele Goodwin of the University of Minnesota Law School for her invaluable guidance, without which I could not have finished this paper. While she provided many useful comments, any mistakes are my own.
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Syndrome (AIDS) referred to the disease as “gay cancer” or “Gay-Related Immune Deficiency.” One physician with the CDC even made an early claim that AIDS posed no threat to heterosexuals. By September 15, 1982, when the CDC defined AIDS as a disease that destroyed a person’s immune system and left him vulnerable to PCP, Kaposi’s sarcoma (KS), and/or other opportunistic infections (OI), there were 593 reported diagnoses of AIDS and 243 of those diagnosed had already died. The disease had spread to 27 states and the District of Columbia; there were also 41 cases of AIDS reported in ten countries in addition to the United States.

Within those first 15 months of the epidemic, this previously “gay only” disease had been reported in hemophiliacs, intravenous drug users (IDUs), Haitians, and children born of mothers with AIDS. A fear that the heterosexual majority was now at risk swept the nation and the world; that panic was amplified by the fact that doctors still knew very little about the disease. Doctors soon learned that AIDS was spread through sexual intercourse and tainted blood, but it was not until May 1983 and April 1984 that French and American doctors, respectively, discovered Human Immunodeficiency Virus (HIV), the virus that causes AIDS. Despite the knowledge that anyone could become infected with AIDS, many Americans still considered AIDS to be a gay disease, in effect creating a medicalized form of homophobia.

In Part I, I provide the social underpinnings in which the AIDS Coalition to Unleash Power (ACT UP) was born. ACT UP was not the first AIDS organization in the epidemic, yet it was one of the first organizations to transition from providing care to People With AIDS.

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8 Lawrence K. Altman, Rare Cancer Seen in 41 Homosexuals, N.Y. Times, July 3, 1981.
9 While AIDS affects men and women, the earliest reports of the disease were in men, as such I will use the gendered pronouns he, him, and his in reference to early individuals diagnosed with AIDS.
11 Id.
13 See Robin Herman, A Disease’s Spread Provokes Anxiety, N.Y. Times, Aug. 8, 1982.
17 Kaye Wellings, Perceptions of risk, media treatment of AIDS, in Social Aspects of AIDS 83, 87 (Peter Aggleton and Hilary Homans eds., 1988). Although AIDS was represented in many different populations, Wellings reported that hemophiliacs became the “innocent victims” of the AIDS epidemic, whereas many believed gay men deserved the disease as a result of a hedonistic lifestyle.
(PWAs)\textsuperscript{18} to a politicized, confrontational AIDS-rights organization. I also explain some of the reasons why ACT UP emerged. Part II addresses zaps\textsuperscript{19}, one of the most memorable techniques utilized by ACT UP to build credibility within the scientific and research communities. ACT UP also relied heavily on political theater and politicized art, and in Part III, I attempt to explain how they were used to promote education on HIV/AIDS and general sexual health. Part IV examines ACT UP’s transformation of emotion into enraged action, specifically ACT UP’s protest of the Food and Drug Administration (FDA) to change how drugs were tested and approved for use. Part V follows with a discussion of one of ACT UP’s main political goals—a government-coordinated and –run AIDS research project with the aim of eradicating AIDS. Finally, I conclude by seeking to relate what ACT UP teaches us about how non-traditional policy and law are made through rigorous patient advocacy and what that can mean for other groups. Although this paper focuses on ACT UP’s actions from 1987 through 1994, ACT UP is still actively involved in HIV/AIDS policy and care in many cities across the U.S. and worldwide.

Part I: The Founding of ACT UP

According to Larry Kramer, one of the founding members of ACT-UP, the sheer numbers of HIV/AIDS diagnoses was causing a panic among the gay men of New York City in the late 1980s.\textsuperscript{20} By December 1987, researchers and physicians had diagnosed AIDS in 128 and territories\textsuperscript{21} and there were an estimated 71,751 cases internationally.\textsuperscript{22} The early figures were shocking; physicians in the United States diagnosed over 47,000 people with AIDS,\textsuperscript{23} and eight other countries reported over 1,000 diagnoses.\textsuperscript{24} Furthermore, the World Health Organization (WHO) recorded five to ten million people were living with HIV worldwide, it predicted 150,000 diagnoses of AIDS by 1988, and close to 3 million cases of AIDS by 1992.\textsuperscript{25} In a speech in March 1987, Kramer implored gay men to pay attention to the massive AIDS casualties and express their rage through organized queer\textsuperscript{26} politics.\textsuperscript{27} It was this initial rage and an overall lack of public awareness that pushed Kramer to form ACT UP soon after.\textsuperscript{28} He wanted to address the growing need for systematized political action, reform how PWAs were treated and change the way AIDS was being dealt with in the United States.\textsuperscript{29} ACT UP partially arose from queer PWAs’ frustrations with AIDS groups such as the Gay Men’s Health Crisis (GMHC) that refused to take an active political stance against

\textsuperscript{18} “People With AIDS” is the term preferred by man individuals diagnosed with AIDS, reflecting a movement of self-empowerment rather than a passive condition (“AIDS patient”) or negative state (“suffering from AIDS”). \textit{See Denver Principles, supra} note 4.

\textsuperscript{19} Zaps will be defined and explained in Part II.


\textsuperscript{22} Id.

\textsuperscript{23} Id. WHO reported 47,022 cases of AIDS in the United States by December 1987.

\textsuperscript{24} Id. Brazil (2,102), Canada (1,334), France (2,674), West Germany (1,486), Italy (1,104), Uganda (2,369), the United Kingdom (1,123), and Tanzania (1,608).

\textsuperscript{25} Id.

\textsuperscript{26} I use “queer” to refer to lesbian, gay, bisexual, transgendered peoples and other sexual and gender minorities as a whole. The use of more specific identifiers, such as “gay” or “lesbian” is intentional.

\textsuperscript{27} Kramer, \textit{supra} note 17 at 135.

\textsuperscript{28} Id.

\textsuperscript{29} Id.
HIV/AIDS. The GMHC sought government funding and private donations and feared a politicized response to HIV/AIDS would prevent the organization from receiving the funds necessary to survive, especially if it was taken against the politicians and political bureaucracies that PWAs felt were denying them service and care. Additionally, many of the AIDS organizations in existence seemed to spring forth with pre-existing boards, goals and a hierarchy; they merely sought supporters and individuals to carry out actions, but did not want input from those supporters. Early ACT UP activists like Maxine Wolfe noted that these apolitical AIDS organizations worked closely with the police and left little decision-making up to those demonstrating:

GLAAD [Gay and Lesbian Alliance Against Defamation] soon formed and immediately became a bone of contention because it started doing these very orchestrated demonstrations. By “orchestrated,” I mean they negotiated with the cops, they basically told you when to show up, when to go home, and there was absolutely no input from anybody into what was going to be done. The board of directors made the decisions.

It was this anger, both at AIDS and with the queer AIDS organizations that failed to work with individual PWAs, that sparked Kramer’s March 1987 speech and the birth of ACT UP. A few months later, in June 1987, ACT UP made its bold debut at the Gay Pride March, sparking a surge in membership. ACT UP marched as a moving concentration camp, complete with wire barrier, men in masks and military gear, and ACT UP’s soon-to-be famous logo—SILENCE=DEATH. ACT UP utilized the apolitical and oft commercialized New York City Gay Pride March as the canvas for their deliberate insertion of a highly political and controversial message. ACT UP sought to turn the pain, fear and grief many queers felt since the start of the epidemic into rage and action. According to Maxine Wolfe, ACT UP “was a whole group of people…ready to do something. They were looking for a kick in the ass and needed an event to be at together, that would lead to that, and that was it.” The language of the ACT UP Working Document captured that rage by describing the organization as “a diverse, nonpartisan group of individuals united in anger and committed to direct action to end the AIDS crisis. We protest and demonstrate; we meet with government and public health officials; we

31 Id.
32 Id.
33 Id.
34 Id.
35 Id. The symbol originally created by six artists in a collective called Gran Fury was the phrase “SILENCE=DEATH” in white letters on a black background. The lettering sat underneath the pink triangle used by the Nazis to label homosexuals (although Gran Fury turned it so the triangle pointed up). “Here, ACT UP takes a symbol used to mark people for death and reclaims it. They reclaim, in fact, control over defining a cause of death; the banner connects gay action to gay survival, on the one hand, and homophobia to death from AIDS, on the other. ACT UP’s common death spectacles repeat the inversion.” Josh Gamson, Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement “Newness”, 36 Soc. Probs. 351, 361. See also Jesse Green, When Political Art Mattered, N.Y. Times, Dec. 7, 2003 at 6 for commentary on why inverting the Nazi’s pink triangle was important.
36 Sommella, supra note 26.
37 Id.
38 Id.
research and distribute the latest medical information; we are not silent."³⁹ Finally, following the theme of Kramer’s formative speech, ACT UP was meant to “organiz[e] the unorganized” and to get “people [to] do[ ] stuff for themselves.”⁴⁰

Since many of ACT UP’s members were disaffected by AIDS organizations that failed to consider their input, ACT UP’s methodology developed organically from its weekly meetings.⁴¹ ACT UP’s main decision-making body is its general membership body; all proposed policies and actions must be approved by the general body before being adopted by ACT UP.⁴² The Coordinating Committee serves as an administrative advisor to the general body, primarily authorizing expenses, reviewing literature and publications by the group, coordinating subcommittees and planning agendas for general meetings.⁴³ The Coordinating Committee, however, is subject to the interests of the sub-committees they represent and the general body itself—the members of the Coordinating Committee will only remain on the Committee for as long as the sub-committees they represent believe they are effective.⁴⁴

Yet, it was not just the grassroots style of involvement that drew people to ACT UP. ACT UP’s members were also tired of the slow, normative methods of activism in use at the start of the AIDS epidemic. ⁴⁵ They were also frustrated with politicians’ failure to represent their interests.⁴⁶ ACT UP’s members were angry and ACT UP capitalized on this anger by directing it into many different forms of action, including zaps, politicized art, emotionally charged protests, and lobbying for a Manhattan Project for AIDS. Most of these forms of activism were not new, but they soon became closely associated with ACT UP, AIDS and queer street activism in the 1980s and 1990s.⁴⁷

Part II: Zaps

Zaps had been used by queer rights organizations for many years before being appropriated by ACT UP.⁴⁸ Arthur Bell, one of the founding members of Gay Activists Alliance, wrote on zaps:

Gays who have as yet no sense of gay pride see a zap on television or read about it in the press. First they are vaguely disturbed at the demonstrators for "rocking the boat"; eventually, when they see how the straight establishment responds, they feel anger. This anger gradually focuses on the heterosexual oppressors, and the gays develop a sense of class-consciousness. And the no-longer-closeted gays realize that assimilation into the heterosexual mainstream is no answer: gays must

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⁴⁰ Sommella, supra note 26.


⁴³ Original Working Document, supra note 35.

⁴⁴ Id.


⁴⁶ Id.

⁴⁷ See generally id.

⁴⁸ Id. at 351.
unite among themselves, organize their common resources for collective action, and resist. 49

The zaps used by ACT UP were premised on the same principle—uncover heterosexual bigotry toward PWAs in an effort to unite queer PWAs in the combat against AIDS. Zaps forced people who supported policies detrimental to PWAs to explain themselves, to change their policies and to sabotage their public image. 50

One of the ways in which ACT UP was able to zap political leaders and public figures was through the art of “Republican Drag.” 51 Wolfe described Republican Drag as “pretend[ing] to be almost anything…to get in somewhere.” 52 ACT UP used costume and theatrics to gain entry into semi-public places and events before revealing themselves and zapping public officials. 53 The rationale was that standing outside of a building and handing out leaflets or protesting required passersby to be receptive to ACT UP’s message, but by invading spaces in which ACT UP (and AIDS) was not supposed to be disrupted these AIDS-free spaces and commanded the attention of the people occupying those spaces. 54 Possessing these places, and using Republican Drag to do so, caused public officials to lose their composure and ACT UP capitalized on those moments to solidify queer support in the fight against AIDS. 55

On the other hand, not all of ACT UP’s zaps were intended to increase the ire of the heterosexual majority and strengthen queer solidarity; zaps directed at science and health professionals were used as analytical brainstorming sessions for the future of AIDS research. 56 Some in the scientific community believed ACT UP’s zaps were initially “hypercritical and negative, [and] not very constructive,” but the zaps eventually shifted into informative sessions in which ACT UP members identified new research and brought possible drug trials to the attention of scientists. 57 In fact, ACT UP’s Treatment and Data Committee insisted that the first thing any individual member must do is to “know [their] shit” before attending a zap with a scientist or health care professional. 58 Specifically, ACT UP recommended that anyone participating in a zap should have detailed files about each drug, including both its positive and negative effects; members were also to acknowledge when there was very little information available. 59 Steven Epstein noted ACT UP members’ transformation into scientific “experts” lent credibility to their zaps and allowed ACT UP to get in the doors of the institutions of biomedicine. Once they could converse comfortably about viral assays and reverse transcription and cytokine regulation and epitome mapping, activists increasingly discovered that researchers felt compelled, by their own norms of discourse and behavior, to

49 Larry Gross, Up From Invisibility: Lesbians, Gay Men, and the Media in America 46 (Columbia Univ. Press 2002).
50 See Sommella, supra note 26.
51 Id.
52 Id.
53 Id.
54 Id.
55 See id.
57 Morgan, supra note 51.
59 Id.
consider activist arguments on their merits.\textsuperscript{60} The use of scientific credibility in zaps saw an early success when ACT UP convinced major health insurance providers to cover aerosolized pentamadine isethionate, a preventative treatment for PCP. Pentamadine had been used in an injected form to treat PCP, but after evidence started to show that an aerosolized treatment could prevent PWAs from contracting PCP in the first place, ACT UP pushed for health insurance providers to cover the aerosolized form.\textsuperscript{61} It also partnered with physicians and AIDS researchers in its presentation of scientific evidence to insurers, eventually convincing many Boston and New England insurers to cover the treatment.\textsuperscript{62}

**Part III: Political Theater and Politicized Art**

**A. Using political theater to encourage sex education**

ACT UP did not, however, only single out influential individuals to change policies or make treatments more accessible. ACT UP also targeted wider audiences and sought to change public perceptions about HIV/AIDS and sex in general. Large spectacles and political theater were meant to affect how individuals talked about issues at home.\textsuperscript{63}

Wolfe was one of the early members of the ACT UP Women’s Committee and tried to continuously spread HIV/AIDS awareness to women.\textsuperscript{64} In 1988, AIDS was the number one killer of women ages 25-34 in New York City, but there had yet to be an important push to make women and the public aware of the dangers of unsafe heterosexual intercourse and intravenous drug use for women.\textsuperscript{65} On the rare occasion there was publically-consumable information directed at women, it placed the onus on them to ensure men wore condoms during sexual intercourse, rather than making it an issue for both genders. According to Wolfe, heterosexual men were not responsible for their own safety or condom usage; it was the women they were sleeping with who needed to insist on safer sex methods.\textsuperscript{66} It was public information campaigns reminded women to never leave home without condoms that drove this message home.\textsuperscript{67} In an effort to educate heterosexual men and women about HIV/AIDS transmission and to make men more responsible for their own health, ACT UP sought to engage them with a piece of political theater in a traditionally heterosexual (male) environment.\textsuperscript{68}

In the spring of 1988, ACT UP’s Women’s Committee brought ACT UP’s message of safe heterosexual sex to the people watching a baseball game at Shea Stadium.\textsuperscript{69} Individual activists purchased tickets to a Mets’ game in three different blocks in three different parts of the U-shaped stadium.\textsuperscript{70} In a call-and-response type fashion, the activists unfurled large signs with

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\textsuperscript{60} Epstein, \textit{supra} note 51. Emphasis in the original.  
\textsuperscript{63} See generally Sommella, \textit{supra} note 26.  
\textsuperscript{64} Sommella, \textit{supra} note 26.  
\textsuperscript{65} \textit{Id.}  
\textsuperscript{66} \textit{Id.}  
\textsuperscript{67} \textit{Id.}  
\textsuperscript{68} \textit{Id.}  
\textsuperscript{69} \textit{Id.}  
\textsuperscript{70} \textit{Id.}
white lettering on a black background, reading: “Don’t balk at safe sex,” “AIDS kills women,” “Men! Use Condoms,” “Strike out AIDS,” “No glove, no love,” and the ACT UP logo, “SILENCE=DEATH” under an up-turned pink triangle. The messages and the very public theatrics of the event were meant to convince sports fans of the need for comprehensive sex education. With just the warning that ACT UP would be at the game, Shea Stadium’s head of public relations met with ACT UP leaders to put ACT UP’s flyers in each press packet and allowed ACT UP members to hand out flyers with information on how HIV/AIDS affected women to each spectator attending the game. ACT UP’s Shea Stadium political theater not only captured the attention of the 20,000 people at the game, but also the thousands more who watched on C-Span.

Although ACT UP believed comprehensive sex education could slow the spread of HIV, there was a large pushback from many Americans to ACT UP’s message. Some were concerned that increased sex education would lead to promiscuity and increased and earlier sexual activity among children and teens. Many scientific studies, however, show no correlation between safer-sex curriculum and an earlier sexual debut or a more promiscuous lifestyle. Furthermore, the claim that abstinence-only education reduces teen sexuality is unsupported by scientific evidence. Even if comprehensive sex education led to increased sexual activity among teens and children, condemnation of such activity makes implied normative judgments about what the “appropriate” age is for teens to engage in consensual intercourse, what the “appropriate” frequency of intercourse is for teens, and what the “appropriate” number of sexual partners is.

While there should be an emphasis on teenagers waiting to have sex until they are emotionally mature enough to do so, bringing morality into teenage sexuality may cause a considerable number of problems. One of the most apparent problems is that determining for teens when they are ready to engage in consensual intercourse is a paternalistic approach to sex. Provided they have sufficient education about the risks and dangers associated with sex, teenagers should be able to exhibit sufficient responsibility and forethought to make appropriate decisions regarding intercourse. Teens are trusted to care for younger children, to drive, and to work in a variety of industries. It is not so great a leap to trust teens to be responsible enough to make wise decisions about their own sexual health if they are well-educated and have a system of support. In fact, statistics show that teens and children without sexual education (abstinence-only education), are more likely to be unprepared for sexual intercourse when it does happen, increasing the risk of HIV/AIDS.

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71 The signs appeared as if the letters were floating on their own because the black background blended in to the darkness while the lights reflected off the lettering.
72 Sommella, supra note 26.
73 Id.
74 Id.
76 Id.
78 See Schemo; Brody; Beil; Sessions Stepp, supra note 72. See also Sex Education in America, supra note 70.
79 Interview with Cathy Strobel, Assoc. Dir. of Health Education, Minn. AIDS Project, in Minneapolis, Minn. (Apr. 1, 2011).
Additionally, passing normative judgments about teen sexual intercourse can lead to stigmatization of sexually active teenage women while sexually active teenage men escape social disfavor. Although anyone who is sexually active is at risk for contracting HIV or other sexually transmitted infections (STIs), only women can become pregnant. Under a formalized, morality-based system of abstinence education, teens that are sexually active run the risk of getting pregnant, but it is only the woman who will show physical signs of having engaged in intercourse. Due to modern medical advances in HIV/AIDS and other STI health care, there are rarely physical signs that a teen has lost his or her virginity other than pregnancy. Presuming a strong societal norm against sexually active teens, men will be able to pass as sexually inactive and, as such, will reap the privilege of being “moral.” Women, on the other hand, run a much higher risk that they will be stigmatized for their choice to engage in sexual activity. Furthermore, even if a teenage man admits to his sexual experience, there will be no physical reminder constantly displaying his violation of societal norms. Finally, women who do not become pregnant are still marked by their sexual experiences with a broken hymen.

B. Politicized art

Beyond Shea Stadium and the push for sex education, ACT UP capitalized on the privilege and artistic background of AIDS’ first major group of victims—gay men. It utilized their talent to create politicized art and used it to convey other ACT UP needs, such as a radical shift in the public perception of AIDS: “But AIDS made its debut among a very cultured group of people. Many were artists who, devastated and enraged, turned their professional skills to protest...But even those gay men who were not culture mavens by trade were knowledgeable amateurs.” These artistic gay men, many of whom were members of ACT UP, used their art and street theater to gain attention and bring their demands to the non-queer masses.

The art was meant to convey specific messages and to instigate action against the institutional constraints that arguably worsened the AIDS epidemic. For example, ACT UP chained themselves to drug company’s headquarters; stenciled bloody hands everywhere, as if to highlight the “governmental guilt in promoting a blood-borne disease;” and covered Jesse Helm’s house in a giant condom in order to show “prejudice [was] as insidious a danger to society as H.I.V. [sic].” Jesse Green of the New York Times argues that this art was successful, in that those outside the populations hardest hit by AIDS could attach a “human face” attached to AIDS. Although the art humanized AIDS, the rendition was often made into a more palatable (and at times an untruthful) face. Even with this sanitization of the “face” of AIDS, the artistic

80 For an analysis of HIV and pregnant women, see Michele Oberman, Test Wars: Mandatory HIV Testing, Women, and Their Children, 3 U. Chi. L. Sch. Roundtable 615 (1996). Oberman’s work touches upon the implications of mandatory HIV testing of pregnant women as part of the state’s police power, especially in light of data that pregnant women with HIV who take azidothymidine (AZT) reduce the risk of transmitting HIV to their fetuses.
81 Green, supra note 31.
82 Id.
83 Id.
84 Id.
85 Id.
86 Id.
87 Id. Green notes that many of the more mainstream artistic representations of AIDS, especially those that put a “human face” to AIDS, were contextually dishonest. The made-for-television movie An Early Frost’s protagonist was gay lawyer who tells his conservative family that he both has AIDS and is gay. The protagonist was an innocent and sympathetic character, as he was infected by his partner’s infidelity and, despite initial close-mindedness by his father, is accepted by his family. Further, the protagonist was “so sanitized as to make his disease and especially his gayness…almost nonexistent. Which is exactly why it worked.” The Ryan White Story
representations made queers more acceptable members of society and simultaneously transformed the purpose of the original confrontational art of ACT UP into a movement for queer inclusion: “At the beginning of AIDS, artists humanized the disease and engaged people’s instincts for self-preservation by appropriating comfortable, popular forms of expression…Within about a decade, that appropriation neutralized the artists’ ability to make further change; the message itself…became comfortable and popular.” As a result, AIDS is still a global epidemic, but the luster of AIDS has dimmed. It is possible that art’s loss of potency in AIDS activism has shifted concern from HIV/AIDS onto other causes.

Part IV: Emotionally-Charged Protests

A. Underlying source of anger

ACT UP was also extremely adept at transforming PWAs’ sorrow and other emotions into rage and directng that rage into action. The intense anger that fueled these zaps, protests, and politicized art was due, in part, to the government’s seeming avoidance of the AIDS epidemic. Ronald Reagan was the president during the first eight years of AIDS, but it was not until April 2, 1987, that he first publically spoke the word “AIDS.” ACT UP sought to engage these frustrated and angry queers and materialize that anger as action; yet, ACT UP was often met with stiff resistance:

Anger takes on an especially negative cast when expressed by people marked as “other” by mainstream society, particularly when large numbers of such people are purposefully taking to the streets and breaking the law in order to disrupt “business as usual.” ACT UP also confronted an American ideology of democracy that locates legitimate political activity in the voting booth and the halls of legislatures and maligns street activism as unnecessary and extreme, a threat to social order. As well, ACT UP existed in a moment when other progressive oppositional movements had disappeared or were in quick decline. Given this context, ACT UP had to make angry street activism a normative and legitimate route for lesbians and gay men.

It was not just heterosexuals or people without HIV/AIDS that opposed public rage; earlier queer activists also feared anger could threaten what social standing and acceptance queers had achieved up to that point. Eventually, however, ACT UP became known for channeling these intense emotions into protest.

also provided American masses the ability to see AIDS playing out on a non-homosexual 13-year-old Midwestern boy. Ryan White was another innocent victim of the AIDS crisis after contracting the disease from a blood transfusion due to his hemophilia. One of the last major humanizing AIDS films was Philadelphia, in which a gay lawyer with AIDS is wrongfully terminated and represented by a homophobic attorney. The inclusion of the homophobic attorney was to provide audience members with a relatable character and reinforce the stereotype that the AIDS epidemic was characterized by heterosexuals coming to infected gay men’s aid.

87 Id.
90 See Gould, supra note 82 at 9-14.
91 Id. at 3.
92 See DeParle, supra note 37.
B. Successful use of anger at the Names Project Quilt, storming of the FDA and the parallel track trials

Some of the foundational policy goals of ACT UP revolved around drugs and medication was one place where ACT UP saw a successful use of PWA anger to effect policy change. The medication goals included improved access to previously approved drugs through lowered prices, increased access to drug trials and research, and speedier approval of drugs by the FDA. The importance of medication and drugs was easily understandable—PWAs were dying without access to medication and many would die before the slow FDA approval process could be completed for new drugs. Despite the sometimes bleak prospects, ACT UP saw some of its greatest successes in the medication field. ACT UP shamed many pharmaceutical companies into lowering prices, established parallel track studies for AIDS medication, and convinced the FDA to speed up its approval for medication.

It was at the Names Project Quilt on display at the national Mall in 1988 where ACT UP capitalized on peoples’ emotions to fight for better access to drugs.\(^93\) The quilt was a memorial for those who had died of AIDS and it served as a site of grief.\(^94\) ACT UP handed out leaflets to those who came to see the quilt in an effort to get the mourners’ enraged.\(^95\) ACT UP’s flyers asserted that it was the government and its inaction that had murdered the PWAs; it was not their disease, but the government’s negligence and slow movement that killed their loved ones.\(^96\) ACT sought to engage the PWAs’ and mourners’ anger by bringing a protest to the FDA and the regulatory system that had prevented PWAs from accessing the medications necessary to forestall their deaths.\(^97\)

ACT UP encouraged the people it met at the Names Project Quilt to storm the FDA in an effort “to dramatize what they called the criminally slow pace of the federal bureaucracy to approve new drug treatments for AIDS.”\(^98\) Over 1,200 PWAs protested for nine hours, blocking exits and preventing anyone from entering or leaving the building.\(^99\) Throughout the protest, over 175 enraged participants were arrested.\(^100\) ACT UP’s protest was a way to force the FDA to increase access to medications through experimental trials and to speed the process of drug approval.\(^101\) At the time, only azidothymidine (AZT) was approved to treat the symptoms of AIDS, but the drug was extremely toxic and had dangerous side effects.\(^102\) There were, however,

\(^93\) Gould, supra note 82 at 6-7.
\(^94\) Id.
\(^95\) Id.
\(^96\) “ACT UP passed out a leaflet at the Quilt showing. One side blared: “SHOW YOUR ANGER TO THE PEOPLE WHO HELPED MAKE THE QUILT POSSIBLE: OUR GOVERNMENT.” Text on the reverse read: The Quilt helps us remember our lovers, relatives, and friends who have died during the past eight years. These people have died from a virus. But they have been killed by our government’s neglect and inaction…More than 40,000 people have died from AIDS…Before this Quilt grows any larger, turn your grief into anger. Turn anger into action. TURN THE POWER OF THE QUILT INTO ACTION.” Id. at 7.
\(^97\) “ACT UP’s logic both acknowledged, and offered a resolution to, lesbian and gay ambivalence about self and society: given our grief and under these dire circumstances where we and our loved ones are being murdered by our government, anger and confrontational activism targeting state and society are legitimate, justifiable, rational, righteous, and necessary. ACT UP offered an emotional and political sensibility that simultaneously acknowledged, evoked, endorsed, and bolstered lesbians’ and gay men’s anger.” Id.
\(^100\) Loth, supra note 92.
\(^101\) Susan Okie, AIDS Coalition Targets FDA for Demonstration; Activists Protest Restrictions on Releasing Experimental Drugs to Severely Ill, Wash. Post, Oct. 11, 1988 at A17.
\(^102\) Loth, supra note 92.
more than 80 other AIDS treatments being tested in experimental trials throughout the United States, but the FDA refused to use the fast-track system to release drugs after Phase II studies were completed, as AZT had been.103

Despite the seemingly rude or offensive techniques, ACT UP managed to convince the FDA to change how it approved drugs and drug trials.104 The FDA and researchers had feared that if experimental drugs were made available before studies were completed, it could cause a drop in the number of drug study participants because anyone could get the drugs from their doctors.105 Despite this fear, Jason DeParle of the New York Times reported that ACT UP’s “fits” significantly sped up the approval of two new drugs and lowered the price of AZT.106 Even Anthony Fauci, the director of the National Institute of Allergy and Infectious Diseases (NIAID) since 1984 who had once been called “an incompetent idiot” and a “monster” by Kramer, credited ACT UP with changing how many people could access drug trials.107 Specifically, Fauci admitted ACT UP played a large role in shrinking the timeline of a drug’s approval from eight years down to three.108

ACT UP also managed to get access to parallel track programs as a way for PWAs and HIV-positive people who were unable to enroll in controlled clinical trials to gain access to experimental drugs and treatments.109 The parallel track programs allowed researchers to continue to collect data from controlled drug trials while still providing PWAs who did not qualify to participate in controlled trials with access to experimental drugs.110 ACT UP envisaged parallel track to be available to Phase II drugs that were determined to be “tolerably safe” and marginally effective.111 The drugs would be available by consultation with a physician and organizations would collect reaction and efficacy data. Parallel track was approved by the FDA in 1989, and while there is no definitive proof that ACT UP was the agent of change, the approval was close on the heels of ACT UP’s protests at the FDA.112 The FDA Anti-Infective Drugs Advisory Committee also formed the Ad Hoc Parallel Track Working Group and allowed ACT UP to be represented in the group.113 Further, ACT UP also participated with NIAD and sat on its AIDS Research Advisory Committee to “define and implement the Parallel Track [sic] program.”114

C. Informed consent and ethical questions of increased access to drugs and drug trials

103 Okie, supra note 95.
104 DeParle, supra note 37.
105 Id.
106 Id.
107 Id.
108 Frank Bruni, Act Up Doesn’t Much, Anymore: A Decade-Old Activism of Unmitigated Gall Is Fading, N.Y. Times, Mar. 21, 1997 at B.
109 Id.
110 Id.
113 Id.
114 Id.
One of the potential downfalls of ACT UP’s goal of getting more PWAs involved in clinical trials was whether the PWA-participant had given informed consent. George Annas, a legal-medical philosopher, opines that PWAs can never truly give informed consent because the desperation they feel because of their chronic illness prevents them from making an informed decision.\textsuperscript{115} Annas also argues that any PWA that believes he is receiving treatment and not participating in an experimental or risky clinical trial has failed to give informed consent.\textsuperscript{116} These arguments, however, are in direct opposition to ACT UP’s rallying cry “A Drug Trial is Health Care Too!”\textsuperscript{117} For Annas, ACT UP’s belief that clinical trials can and should be used as a form of treatment opens PWAs up to being taken advantage of by earnest researchers.\textsuperscript{118} Annas’ concerns, however, are based off of a researcher-participant model in which the participant is largely left in the dark about the inner workings and risks of the trials. With legal regulations in place that force researchers to reveal their intentions, the known risks, and the suspected benefits, it would strip PWAs of their agency if they were not allowed to give consent to testing merely because of their illness.

Eugene Volokh illustrated this argument by claiming people combating terminal illnesses have a right to medical self-defense, or in the case of PWAs, to participate in clinical trials.\textsuperscript{119} Volokh notes that the Supreme Court held in \textit{Roe. V. Wade}\textsuperscript{120} and \textit{Planned Parenthood of Southeastern Pennsylvania v. Casey}\textsuperscript{121} that a woman had the option to exercise medical self-defense because there must always be an exception for the life and health of the mother.\textsuperscript{122} Even though an abortion performed in medical self-defense may pose a risk to the health or safety of the woman undergoing the procedure, there must be a tangible risk to the woman before a restriction can be enacted.\textsuperscript{123} Extending this argument to PWAs, the government should be required to show a substantial or tangible risk to a PWA before restricting his or her access to a drug trial. Annas’ concern that physicians and researchers will take advantage of PWAs,\textsuperscript{124} however, is based on the presumption that ACT UP’s push for wider involvement in drug trials failed to consider the safety and health of PWAs. In line with abortions’ protections for the health and life of an expectant mother, ACT UP sought access to drugs through parallel track “as soon as a tolerably safe dose range ha[d] been defined and preliminary evidence of efficacy ha[d] been obtained.”\textsuperscript{125} ACT UP and the PWAs advocating for parallel track drug trials wanted to seek out new treatments in order to improve the quality of their lives or forestall their death.

Additionally, Annas argues that it is when a patient is suffering from a terminal illness that he or she cannot give informed consent to participate in an experimental drug trial.\textsuperscript{126} He opines that the researchers use extreme coercion and the PWA is blinded by self-deception,

\textsuperscript{116} Id. at 311.
\textsuperscript{117} Id. at 312.
\textsuperscript{118} Id. at 310-313.
\textsuperscript{119} See generally Eugene Volokh, \textit{Medical Self Defense, Prohibited Experimental Therapies, and Payment for Organs}, 120 Harv. L. Rev. 1813.
\textsuperscript{120} 410 U.S. 113 (1973).
\textsuperscript{121} 505 U.S. 833 (1992).
\textsuperscript{122} Volokh, \textit{supra} note 113 at 1824.
\textsuperscript{123} Id. at 1825.
\textsuperscript{124} Annas, \textit{supra} note 109 at 312.
\textsuperscript{125} \textit{Treatment Access, supra} note 106.
\textsuperscript{126} Annas, \textit{supra} note 109 at 310.
preventing the PWA from making a rational decision with his or her health or life in mind.\textsuperscript{127} ACT UP, however, lobbied and protested the FDA to open up parallel track, meaning there was no coercion on the part of researchers to enroll PWAs into the program. Furthermore, any data collected from PWAs enrolled in a parallel track study is not sufficiently scientifically reliable to be used in a final report because patients with access to parallel track drugs previously failed to meet the criteria needed to perform a valid drug trial.\textsuperscript{128} Finally, the FDA is able to modify the parallel track programs to ensure the drugs available meet certain levels of safety, as first suggested by ACT UP.\textsuperscript{129} 

The concern that PWA participation in clinical trials risks exposure to potentially dangerous medications is a risk that anyone using medication undertakes. Anyone, whether he or she has AIDS, HIV or neither, faces risks on a daily basis—from crossing the street to eating in a restaurant to consuming medication—there is no way to live a completely risk-free life. While clinical trials are used to gather information on how people react to new or unknown medications, these experiments were in place long before ACT UP won access to clinical trials via parallel track. Even with FDA-approved medicines, a doctor cannot guarantee that a patient will not have an adverse and potentially life-threatening reaction to the medication. Prohibiting PWAs from participating in clinical trials because of a fear of exposure to potentially dangerous medicine fails to take into consideration the normal process for FDA approval, which includes human subject participation in clinical trials. Further, as long as PWAs give their informed consent, PWAs have been made aware of the risks of participation in the trial.

Part V: Manhattan Project for AIDS

One of the final policies ACT UP pushed for was the creation of a Manhattan Project for AIDS, or a Manhattan Project II: a government-coordinated, -funded, and -run research program dedicated to discovering medical advances in HIV/AIDS. The official name was the McClintock Project, but it was often called the Manhattan Project II in reference to the highly centralized government-sponsored research and development project to create the first atomic weapon in World War II.\textsuperscript{130} ACT UP sought government involvement because it feared that independent researchers were wasting time performing duplicative work without any regulation or information-sharing.\textsuperscript{131}

ACT UP also wanted increased government funding for HIV/AIDS research and sought fund distribution through a Manhattan Project mechanism.\textsuperscript{132} When HIV was initially discovered in 1983 and 1984, the Secretary of Health and Human Services made the bold claim that there would be a cure for AIDS within two years.\textsuperscript{133} Many in ACT UP saw the government’s failure to find that cure as a direct result of its lack of funding and centralization of

\begin{itemize}
\item \textsuperscript{127} Id.
\item \textsuperscript{128} Treatment Access, supra note 106.
\item \textsuperscript{129} See id. ACT UP did not advocate to an uninhibited access to any experimental drug trial or medical procedure, but rather suggested that there be minimum safety guidelines for the PWAs participating in the Parallel Track.
\item \textsuperscript{130} Steven R. Salbu, \textit{Should AIDS Research be Regulated? A Manhattan Project for AIDS and Other Policy Proposals}, 69 Ind. L.J. 425, 432-433.
\item \textsuperscript{131} Id.
\item \textsuperscript{132} Id.
\end{itemize}
AIDS research. They believed that if the government had actually committed sufficient funds and coordination to researching HIV/AIDS, there would have been substantial progress in the fight against AIDS.

ACT UP’s goal for a Manhattan Project II to streamline HIV/AIDS research was never successful. Despite numerous promises by President Bill Clinton throughout his first presidential campaign, he was still calling for a future coordinated effort to create an AIDS vaccine in 1997. ACT UP was successful, however, in bringing a Manhattan Project for AIDS to the national stage and helped elect Clinton because of his support for PWA rights. The 1992 presidential election, the first in which exit polls asked voters if they identified as homosexual or bisexual, had an estimated four to five percent queer turnout and seventy-two percent of those queer voters voted for Clinton.

After Clinton won the presidency, the AIDS battleground changed. Clinton spent 20% more on AIDS research than his predecessors, nearly $1.3 billion. Clinton also established an outpatient fund named after a teenager who was infected by AIDS after a blood transfusion, Ryan White. In the words of Kramer, “You don’t know where to yell or who to yell at. Clinton says all the right things, then doesn’t do anything.” Indeed, Clinton talked a lot about the need for early AIDS action during his campaign in order to get elected, but it took five months before he named Kristine M. Gebbie as the AIDS Czar, and only after the National Commission on AIDS was prepared to attack Clinton for his failure to follow through on campaign promises.

Gebbie was a former nurse and chief health officer of Oregon and Washington, but she was not the leader ACT UP had hoped for. Her only experiences with AIDS came from her roles on the CDC’s advisory panel on HIV prevention and on the National Commission on AIDS. Gebbie did not see herself as a leader; she saw her job as a short-term coordinator of different federal agencies without any responsibility for engaging in research herself.

The push for a Manhattan Project for AIDS was a result of the “sluggish progress of AIDS research” in the initial years of the epidemic. Although the belief that unrestrained coordination or directed research would speed up the development of a cure or that it would

134 Salbu, supra note 131 at 426.
135 Id.
137 Id.
139 Schmalz, supra note 139.
141 Id.
142 Id.
143 Id.
144 Id.
145 Id. AIDS activists, rather, sought someone such as Jimmy Carter, C. Everett Koop or H. Norman Schwazkopf to lead the government’s response to AIDS.
146 Id.
147 Id.
148 Salbu, supra note 131 at 425.
eliminate redundancies in research, a Manhattan Project might actually have limited the positive aspects of competition in AIDS research. First, any kind of scientific research needs to be examined, reformatted and thought about in a variety of different scientific approaches. If there had been a Manhattan Project for AIDS, it is possible that scientists would be unable to make the breakthroughs or discoveries ACT UP hoped for because of a stifled and limited scope of research. Had the scientists been directed to complete a narrowly defined task, they would not be allowed to jump start dead-end research by consulting information on closely related and potentially helpful areas. Steven Salbu, a legal ethicist, argues that the vaccination or cure for AIDS will come from the vision of someone who sees the problem somewhat differently from the masses of investigators. The end of AIDS will likely accompany a demonstration that the scientists who came before missed something essential, or modeled the disease inaccurately, due to some largely accepted but false paradigm.

The scientific pluralism required for scientific discovery would have been hampered by a government-run program, especially if the government’s assigned tasks were too narrow or constricting.

Competition is also a driving force in scientific discovery and a Manhattan Project for AIDS would have stripped much of the competition to develop AIDS research. Private and public researchers compete for academic achievement, tenure, patents, and financial gain, but the Manhattan Project would require that researchers put aside their competitive drive, lowering their incentive to strive for scientific discovery. The counterargument is that competition destroys cooperation between researchers, which could lessen effective AIDS research. This counterargument fails to recognize, however, that the incentives to compete would drive AIDS researchers to cooperate with one another if the cooperation created a competitive advantage. On the other hand, Salbu posits forced cooperation, as through a Manhattan Project on AIDS, would not foster competition.

A more appropriate solution than the Manhattan Project II would be for the national government to create significant funding streams for HIV/AIDS research without earmarking too much for specific types of research or expected outcomes. If the research grants had more open objectives, the competitive and adversarial aspects of AIDS research would remain, but the desire for increased funding similar to the Manhattan Project for AIDS would also be present.

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149 Id. at 432-433.
150 Id. at 441.
151 Id.
152 Id. at 442.
153 Id. at 446.
154 See id. at 445-446.
155 Id.
156 Id. at 446.
157 Id.
158 As of May 1997, Clinton was spending $1.5 billion on AIDS research and only ten percent was specifically directed toward creating an AIDS vaccine. Mitchell, supra note 124. Clinton also claimed to have tripled AIDS funding while he was president and providing twenty-five percent of global AIDS funding. Peter Baker, It’s Not About Bill, N.Y. Times, May 31, 2009. President George W. Bush, however, set aside $2.5 billion for AIDS research in 2001. Dave E. Sanger, Bush Says U.S. Will Give $200 Million to World AIDS Fund, N.Y. Times, May 12, 2001. Finally, President Barack Obama sought to spend $4.9 billion on HIV/AIDS research. Robert Pear and Gardiner Harris, Obama Proposes Health Agency Cut, a First, but Spares Doctors’ Medicare Fees, N.Y. Times, Feb. 15, 2011 at A19.
Furthermore, with the advent of social networking technology, the possibility of shared data and cooperation for the sake of a competitive advantage could increase. As long as participation in data sharing is voluntary, researchers can incorporate diverse scientific approaches into their experiments and studies only when it will help with scientific discovery.

Part VI: Conclusion

HIV/AIDS is still a global epidemic, although the Joint United Nations Programme on HIV/AIDS (UNAIDS) reports reductions in HIV transmissions and no increases in AIDS-related deaths since 2001. In 2009, UNAIDS recorded 33.3 million diagnoses of HIV, 2.6 million new cases of HIV, and 1.8 million AIDS-related deaths. Further, the CDC believes over one million people in the United States have HIV and 21% of them do not yet know their status. The CDC estimates that 18,000 people will still die from AIDS each year in the United States, and over 576,000 Americans have died since the epidemic began.

ACT UP emerged at a time when people were still petrified of HIV/AIDS, gay people, and dirty blood. This organization’s struggle has inextricably been tied to various other causes and campaigns, including queer rights and patient advocacy, but its greatest impact has still been in the HIV/AIDS community. The way in which ACT UP operated was not new, but it allowed marginalized groups of people to force change outside of the more normative legislative or judicial process. At a time when there were few politicians catering to the PWA vote, ACT UP used methods that made its message heard.

ACT UP has certainly not ended AIDS, but it has had a considerable effect on the HIV/AIDS battleground. ACT UP has radically changed how the FDA conducts drug trials and has expanded PWAs’ access through the parallel track programs. ACT UP was also instrumental in speeding up the drug approval process and getting more drugs available to more people. Most importantly, however, ACT UP has brought greater public awareness to AIDS and made the disease much more human.

While ACT UP’s methods were not perfect, its methodology can be and has been imitated by other marginalized or patients’ advocacy groups seeking change outside the traditional legislative process. ACT UP laid the framework for not only making the public more aware of a disease or injustice by using loud, eye-catching protest and political theater, but it also has pushed groups to work hard to protect their rights. Increasing the visibility of an illness or marginalizing status and using aggressive “expert”-type zaps and emotionally-charged protests can make people in power address concerns that they might not otherwise have considered. The most translatable and effective techniques ACT UP used was as simple as reclaiming agency and shrugging off the negative connotation of suffering or the passive connotation of a patient; ACT UP was an organization of active, loud, People With AIDS.

161 Id.