

STANDING AGAINST A “WILLFUL AND DEADLY NEGLIGENCE”:  
THE DEVELOPMENT OF A FEMINIST  
RESPONSE TO THE  
AIDS CRISIS

by

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## LIST OF ABBREVIATIONS

<b>Abbreviation</b>	<b>Description</b>
ACLU	American Civil Liberties Union
ACT UP	AIDS Coalition to Unleash Power
AMA	American Medical Association
AIDS	Acquired immune deficiency syndrome
CDC	Center for Disease Control
FDA	Food and Drug Administration
GMHC	Gay Men's Health Crisis
GRID	Gay-Related Immune Deficiency
HIV	Human immunodeficiency virus
LAP	Lesbians AIDS Project
NIH	National Institute of Health
NOW	National Organization of Women
SSA	Social Security Administration

## I. INTRODUCTION: “WOMEN DON’T GET AIDS. THEY JUST DIE FROM IT.”

By the early 1990s, female activists in the AIDS Coalition to Unleash Power (ACT UP) in New York City were fed up with the still-prevailing assumption that AIDS took only white male victims. While women, particularly poor women, constituted a growing percentage of those with the disease, they remained largely excluded from medical research and treatment.<sup>1</sup> Women’s exclusion amounted to, as one activist group put it, “nothing short of willful and deadly negligence.”<sup>2</sup> Activists identified the ways that such “willful and deadly negligence” created a range of peculiar obstacles blocking women from accessing equal treatment in medical research or even basic medical care. To make matters worse, even their best allies in other AIDS activist organizations either could not, or would not, incorporate women AIDS victims as full partners in their burgeoning movement. Women, therefore, took it upon themselves to change the national conversation around AIDS. For instance, in order to call attention to the devastating effects of this negligence, a group of activists unleashed a powerful billboard campaign across New York City. “Women don’t get AIDS,” the signs at bus stops read, “they just die from it.”<sup>3</sup> Through this campaign and a myriad of their other activities, the women in

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<sup>1</sup> Subjects, Federal, Jan.-Dec. 1991. January-December, 1991. MS ACT UP: The AIDS Coalition to Unleash Power: Series VIII. Subjects Box 84, Folder 8. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tPMD1>. Accessed 4 Feb. 2018.

<sup>2</sup> Ephemera, Flyers, Handbills by ACT UP, Miscellaneous, 1988-1991. 1988-1991. MS ACT UP: The AIDS Coalition to Unleash Power: Series XI. Ephemera, Flyers, Handbills by Act Up Box 195, Folder 24. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tPMw2>. Accessed 4 Feb. 2018.

<sup>3</sup> Gran Fury, *Women Don’t Get AIDS They Just Die From It*, poster. (New York City: various locations, 1991). Posters can be viewed online through the Public Art Fund at

ACT UP joined many others in the fight against the invisibility of women living with AIDS.

The women in ACT UP used mass demonstrations, media, and legal campaigns to demand recognition that women were getting and dying of HIV/AIDS. By the middle of the 1990s, women in ACT UP had raised awareness for women with AIDS and sued the federal government for withholding disability benefits from women with AIDS, lobbied to change the Center for Disease Control's definition of AIDS, and won the inclusion of women in medical research related to the disease. After leaving ACT UP, these women turned to new places for their activism, but remained true to their convictions that gender inequality lay at the root of government's and public's misunderstanding of the AIDS crisis in women. AIDS activists achieved all this by bringing attention to and fighting the results of the sexist political and medical systems that discriminated against women with AIDS. By drawing on their own experiences as marginalized women as lesbians, as well as successful yet often frustrated activists, and by embracing an understanding of the interwoven oppressions at work in lives of women with AIDS, women in ACT UP converged within the mostly male organization to raise awareness for women victims of the disease. Together, they managed to challenge the agencies that prevented women from accessing care, and ultimately pushed ACT UP and AIDS activism to advocate for women with AIDS. However, activists remained unsatisfied in ACT UP and used their experiences to go in new directions to better serve women with AIDS.

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[https://www.publicartfund.org/view/exhibitions/5735\\_women\\_dont\\_get\\_aids\\_they\\_just\\_die\\_from\\_it#&gid=1&pid=2](https://www.publicartfund.org/view/exhibitions/5735_women_dont_get_aids_they_just_die_from_it#&gid=1&pid=2). Accessed January 11, 2018.



This thesis examines how women came together in ACT UP's first New York chapter and combined their experiences in previous movements and their understandings of how race, gender, poverty, and sexuality overlapped to transform AIDS activism in New York City. This work brings attention to women's health care activism in the 1980s and 1990s to demonstrate how and why women became activists. I will show that female AIDS activists converged in ACT UP, bringing their own histories of activism and experiences as marginalized women, and refined each other's politics. As a result of this convergence, women introduced new debates and conflicts into the group that challenged ACT UP's coalition of men and women of varying sexualities, races, backgrounds, and goals. These conflicts, while essential to refining ACT UP's politics, spurred a process of fragmentation in which women left ACT UP and turned to new fields or returned to the fields they came to ACT UP from, like service work, the law, media, art, and academia. Throughout this process, from 1987 onward, the women who had transformed ACT UP argued that sexism and racism were the fundamental problems prohibiting women with AIDS from accessing care. Through their work in the AIDS crisis, activists pushed for visibility, care, and funding for women living with AIDS and created a more complete understanding of how AIDS manifested in different women which changed the lives of women with AIDS, and opened the door for more nuanced understanding of how AIDS impacted different male communities.

Women were largely invisible in the scientific research of AIDS before 1987. The CDC first reported news of the disease in a June of 1981 *Morbidity and Mortality Weekly Report*. Five young, homosexual men had become sick with *Pneumocystis carinii*

pneumonia (PCP).<sup>4</sup> The CDC raised alarms in the “M and M” report because PCP was incredibly rare. A healthy person’s immune system can fight PCP readily, so for the illness to be the cause of two deaths in seemingly healthy men was worthy of study. Only a few weeks later, the number of cases had grown to twenty-six, leaving the researchers at the CDC befuddled. An unknown malady was wreaking havoc on the immune systems of young, gay men. Because the first known people with the disease were gay, health agencies hypothesized that the patients’ homosexuality was the cause. In May 1982, a *New York Times* article labeled the disease “gay-related immune deficiency” (GRID), while many of the victims of the disease called it “gay plague” or “gay cancer.”<sup>5</sup> Through the gay and straight media, doctors pushed the idea that sexual promiscuity in the gay community was to blame for the spread of the disease.<sup>6</sup>

Gay men too considered the possibility that promiscuity amongst gay men led to the AIDS crisis. Larry Kramer, for example, in a 1981 *New York Native* article articulated his fear that some seemingly innocuous act or instance from years past could prove to be a death sentence.<sup>7</sup> Kramer’s fear was not unfounded, for as John D’Emilio demonstrates, a key component of the gay liberation movement of the 1970s was the idea that homosexual identity was not shameful, but something to embrace. In his larger examination of the homophile movement of the 1950s-1960s, D’Emilio argues that the Stonewall Riots of June 1969, in which the young patrons of the Stonewall Inn and 2,000

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<sup>4</sup> Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley: University of California Press, 1993), 45.

<sup>5</sup> Ibid., p. 46.

<sup>6</sup> Ibid.

<sup>7</sup> John D’Emilio, *The World Turned: Essays on Gay History, Politics, and Culture* (Durham: Duke University Press, 2002), 71.

other diverse supporters fought off a police force of 400, sparked a nationwide grassroots movement for gay and lesbian liberation.<sup>8</sup> Rooted in this much longer history of the homophile movement, the movement for liberation had lasting implications, including the removal of homosexuality from the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, to the repeal of sodomy laws across the country.<sup>9</sup> During the 1970s, gay men and lesbians combined resistance with sexual freedom to enact meaningful change. However, their successes would be challenged with the election of Ronald Reagan in 1980 and the Supreme Court's *Bowers v. Hardwick* decision that upheld a Georgia state law making sodomy illegal.<sup>10</sup>

As president, Ronald Reagan first remained silent on the topic of AIDS. In fact, it was not until over 25,000 people had died from the disease before he even uttered the phrase in 1985.<sup>11</sup> According to biographer Lou Cannon, First Lady Nancy Reagan spurred on Reagan's first speech on the topic, in May of 1987, not the president's own concerns.<sup>12</sup> However, as Jennifer Brier argues, Reagan's beliefs in shrinking the federal government, deregulation, and individualism during both terms of his presidency had direct, even if unintended, effects on the AIDS crisis.<sup>13</sup> These beliefs trickled from Reagan down through local governments, which made it more difficult for people, from

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<sup>8</sup> John D'Emilio, *Sexual Politics, Sexual Communities: The Making of a Homosexual Minority in the United States, 1940-1970* (Chicago: University of Chicago Press, 1998), 232.

<sup>9</sup> Ibid., p. 238.

<sup>10</sup> Deborah B. Gould, *Moving Politics: Emotion and Act Up's Fight Against AIDS* (Chicago: The University of Chicago Press, 2009), 121.

<sup>11</sup> Frederic G. Reamer, ed., *AIDS & Ethics* (New York: Columbia University Press, 1991), 161.

<sup>12</sup> Jennifer Brier, "Reagan and AIDS," in *A Companion to Ronald Reagan*, ed. Andrew L. Johns, (New Jersey: Wiley-Blackwell, 2015), 222.

<sup>13</sup> Ibid., p. 226.

directors of federal agencies to people living with AIDS, to adequately respond to the crisis. For example, the Reagan administration refused to add resources to federal agencies, like Health and Human Services, the National Institute of Health, and the Food and Drug Administration.<sup>14</sup> The administration also pushed for the deregulation of industries, including the pharmaceutical industry, which favored industrial capital growth over treatment of people with AIDS.<sup>15</sup> And Reagan's belief in a type of "radical individualism" meant that he and his administration focused on changing individual behavior to stop the spread of the disease, rather than the underlying factors that contributed to increasing rates of transmission of AIDS, like homophobia, racism, and sexism.<sup>16</sup>

While federal agencies sent mixed messages to people about AIDS, people with AIDS and doctors battled over science, power, and knowledge as AIDS patients became "patient-experts" who often challenged doctors over knowledge and expertise.<sup>17</sup> In 1993, sociologist Steven Epstein argued that this change in the doctor-patient relationship grew out of the breakdown of trust between medical experts and laypeople. Epstein frames AIDS in terms of French historian Michel Foucault's concept of the microphysics of power to explain how the scientific expertise of doctors and the experience-based knowledge of patients were in constant negotiation. AIDS subverted the accepted standard that knowledge issued from the "credentialed expert" and was passed down to the layperson. To suggest that patients could be sources of knowledge challenged this

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<sup>14</sup> Ibid.

<sup>15</sup> Ibid., p. 228.

<sup>16</sup> Ibid., p. 229.

<sup>17</sup> Epstein, *Impure Science*, 13.

traditional power dynamic between doctors and patients.<sup>18</sup> People living with AIDS forged a place of power for themselves as the “real” experts when they confronted the doctors and scientists who were failing to progress toward an “effective cure or vaccine.”<sup>19</sup> Patients’ “expertification” undermined claims to “pure science” and began new conversations about the science of AIDS.<sup>20</sup> By demanding inclusion in medical research that recognized their unique situations, people living with the disease emerged as political actors.

While men with AIDS fought for medical and federal responses to AIDS, women with AIDS were still largely invisible in the epidemic. While women made up over ten percent of those diagnosed with HIV in 1990, federal agencies refused to include their unique symptoms in their definitions of AIDS.<sup>21</sup> Despite the growing number of women with the newly-renamed acquired immune deficiency syndrome (AIDS), the CDC refused to alter its definition to include the gynecological symptoms that afflicted most women living with AIDS.<sup>22</sup> In 1982, the CDC explained that it was studying “a disease, at least moderately predicative of a defect in cell-mediated immunity, occurring in a person who has no known cause for diminished resistance to that disease.”<sup>23</sup> While

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<sup>18</sup> Ibid., 4.

<sup>19</sup> Ibid., 7.

<sup>20</sup> Ibid., 13.

<sup>21</sup> SY Chu, JW Buehler, and RL Berkleman, “Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States,” *Journal of the American Medical Association* 264 (1990): 225.

<sup>22</sup> Ruth B. Merkatz, “Women in Clinical Trials of New Drugs: A Change in the Food and Drug Administration Policy,” *The New England Journal of Medicine* 329, no. 4 (July 22, 1993): 294.

<sup>23</sup> R.M. Selik, H.W. Haverkos, and J.W. Curran, “Acquired Immune Deficiency Syndrome (AIDS) Trends in the United States, 1978-1982,” *American Journal of Medicine* 76, no. 3 (1984): 493.

vague, and indicative of the unknown nature of the illness, this definition allowed the agency to continue to collect data. After three years of data collection and, most importantly, the development of the HIV test, the CDC revised its case definition in 1985 to include a list of indicators, such as a positive HIV test and a short list of opportunistic infections often seen in people with AIDS, none of which were gynecological infections.<sup>24</sup> Most women with AIDS did not exhibit one of the five opportunistic infections and remained invisible as people suffering from the illness.

Because the CDC did not take women's symptoms into account, women also could not receive Social Security disability benefits. Social Security was particularly vital to AIDS patients because of the snowball nature of the syndrome. One infection could result in the development of several others so people with AIDS found it increasingly difficult to maintain a job to keep health care coverage. Patients depended upon Social Security in the face of such chronic illness. Yet, because the Social Security Administration (SSA) followed CDC guidelines, only patients with certain manifestations of the syndrome could claim benefits. Exclusion from disability benefits affected women differently, and it was particularly devastating for poor women of color in cities, who, significantly, made up the overwhelming majority of seropositive women. By 1990, over seventy percent of women with AIDS were poor African Americans or Latinas. Women with low incomes already suffered from limited access to health care, medicine, and education. Regular visits to the same doctor who was familiar with the syndrome and its

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<sup>24</sup> U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, Morbidity and Mortality Weekly Report, "Revision of the Case Definition of Acquired Immunodeficiency Syndrome for National Reporting--United States," 34(25): 373-374, 1985.

manifestations in women were essential to the successful treatment of AIDS. For poor women whose only chance at professional and meaningful healthcare came through the administration of disability services; the exclusion from the SSA and CDC had life-threatening consequences.<sup>25</sup>

Like the scientific analysis of AIDS, the traditional AIDS political narrative in the 1980s also tended to overlook women. Widely read histories, literary works, and popular media focused on the trauma of the crisis, highlighting male symptoms, male activism, and male deaths, like Larry Kramer's play, *The Normal Heart*, and journalist Randy Shilts' tome *And the Band Played On*.<sup>26</sup> Randy Shilts, for example, emphasized the homophobia that fueled the conflicts between activists and their antagonists, such as the government officials who responded by shutting down local bathhouses or by preventing gay men from donating blood.<sup>27</sup> Such narrow views of AIDS missed key aspects of the history of the AIDS movement. The first people to write about AIDS did so as part of

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<sup>25</sup> Associated Press, "AIDS Disability Rule Biased, Marchers Say," *Boston Globe*, October 3, 1990.

<sup>26</sup> Randy Shilts' *And the Band Played On* was published in 1987 and was incredibly popular. In 1993, HBO made a movie with the same name based on the book. Likewise, Larry Kramer's play *A Normal Heart*, which premiered in 1985, was also turned into a popular movie in 2014. While Randy Shilts' book has remained one of the most-cited works on AIDS, historian Julio Capó Jr. argues in "Interchange: HIV/AIDS and U.S. History," *The Journal of American History* 104, no. 2 (September 2017), that it was also responsible for many dangerous public misunderstandings about HIV/AIDS. One of those was the "patient-zero" myth, that gay Canadian flight attendant, Gaëtan Dugas, was responsible for introducing the virus to the United States.

<sup>27</sup> Patricia D. Siplon argues in *AIDS and the Policy Struggle in the United States* (Washington, DC: Georgetown University Press, 2002) that even this response was slow, as by the 1980s, the blood industry had considerable pull in the federal policymaking and fought growing governmental and public concerns that the blood supply may have been contaminated with HIV. The industry delayed testing and screening procedures, in addition to issuing recalls of plasma products. This slow response, Siplon argues, was deadly for those who become infected with HIV/AIDS after receiving contaminated blood products.

their work as male AIDS activists who got their start in the gay liberation movement and thus viewed AIDS primarily through the lens of sexual equality. Gay men living with AIDS diagnosed the government's delayed response to the crisis as a symptom of homophobia. For example, activist and writer Dennis Altman argued that the increasing death toll of gay men, which in 1986 sat at 25,000 deaths across the country, in the first years of the AIDS crisis grew largely out of the anti-gay bigotry of President Ronald Reagan's conservative policies.<sup>28</sup>

In the early 1980s, sociologists, political scientists, artists, journalists, and playwrights, most of who were gay men—and all of whom were white—wrote about their personal experiences during the epidemic. They focused on the trauma of losing friends and lovers, and on the constant clashes with local and federal governments. These initial works served an important function by creating a popular understanding of AIDS. Authors responded to the devastation in their communities, who after years of sexual repression were finally coming “out” in public awareness after the liberation of the 1970s. However, as the authors were mostly focused on their own experiences, they served to perpetuate the popular understanding of AIDS as a disease that afflicted white,

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<sup>28</sup> Dennis Altman, *AIDS in the Mind of America* (New York: Anchor Books, 1982), 2. Carroll, *Mobilizing New York*, 141. It is important to note that historian Jennifer Brier argues that while Ronald Reagan was personally disinterested in the AIDS crisis, the actions he took as president did meaningfully change the course of the crisis in “Reagan and AIDS,” in *A Companion to Ronald Reagan*, ed. Andrew L. Johns (Malden, 2014), 221-227. Brier demonstrates that while political histories of Reagan often ignore AIDS, after Reagan's initial reaction of silence, his subsequent actions like deregulating the pharmaceutical and social services industries and allowing C. Everett Koop to create a more scientifically- and less morally-based, federal response to AIDS education that was echoed in the State Department's prevention and treatment efforts in the Global South.



“creative,” gay men.<sup>29</sup> They chronicled the beginning of the crisis, from the CDC’s initial 1981 report on the mysterious illness called gay-related immune deficiency (GRID) to federal agencies’ attempts to restrict the spread of the disease by targeting the larger gay communities in San Francisco and New York.<sup>30</sup> These first AIDS chroniclers focused on their own friend groups and their own experiences with the disease, leaving other populations also devastated by AIDS to appear in their narratives as peripheral actors. The national discourse focused on the very real devastation gay men experienced, which inadvertently placed women in a position of invisibility.

Activists responded to the AIDS crisis by forming a variety of organizations to meet the needs of people with AIDS, but they too were initially focused on gay men. Two of the first and most prominent groups, Gay Men’s Health Crisis (GMHC), founded in January 1982, and AIDS Coalition to Unleash Power of New York (ACT UP), founded in March 1987, provided care and education to people with AIDS in New York City.<sup>31</sup> GMHC formed in Larry Kramer’s apartment in order to create a volunteer base to

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<sup>29</sup> Allan Bérubé examines the association between homosexuality and class privilege and whiteness in his chapter, “How Gay Stays White and What Kind of White It Stays,” in *My Desire For History: Essays in Gay, Community, and Labor History*, ed. John D’Emilio, and Estelle B. Freedman (Chapel Hill, 2011). 202-31. Bérubé argues that that category of “gay men” has become white through a long history of whitening practices from white gay men and anti-gay activists alike. In a brief examination of the whiteness in the AIDS movement, he argues that it was the few white lesbians and people of color who were most outspoken about the movement’s need to become more racially inclusive. The white men in the group, and white gay men more broadly, Bérubé argued, needed to recognize their unintentional whiteness and become dedicated antiracist activists.

<sup>30</sup> Ibid., 33.

<sup>31</sup> Jennifer Brier, *Infectious Ideas: U.S. Political Responses to the AIDS Crisis* (Chapel Hill: University of North Carolina Press, 2009), 157.

provide care for people with AIDS after the deaths of their own loved ones.<sup>32</sup> The men who founded GMHC believed that “homophobic disinterest” by the public, and Ronald Reagan in particular, combined with inaction on the part of gay men fueled the rise of AIDS.<sup>33</sup> In fact, it was not until Rock Hudson’s death in 1985 that Ronald Reagan requested his Surgeon General J. Everett Koop write a public report on AIDS.<sup>34</sup> In those five years of presidential silence, Koop, a conservative, anti-choice pediatrician, later explained that he studied AIDS from a scientific perspective, rather than a traditionally conservative, Christian position.<sup>35</sup>

Koop’s report on AIDS sounded drastically different than what Ronald Reagan had intended, including information on condom use and encouraging “frank” conversations about sex and sexuality.<sup>36</sup> Reagan’s closest confidantes claimed Koop pushed “homosexual propaganda,” and by 1987, the administration argued that AIDS education should center on a more respectable sexuality—one that occurred safely within the confines of monogamous heterosexual marriage.<sup>37</sup> And as the crisis continued, the death toll rose, and the federal government continued to appear disinterested, some people with AIDS or working in AIDS, like Larry Kramer, demanded a different approach. Kramer believed that only activist pressure would force the Reagan administration to respond to the crisis.<sup>38</sup> Thus, ACT UP formed in March of 1987 when

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<sup>32</sup> Philip M. Kayal, *Bearing Witness: Gay Men’s Health Crisis and the Politics of AIDS* (Boulder: Westview Press, 1993), 2.

<sup>33</sup> *Ibid.*, p. 7.

<sup>34</sup> Brier, “Reagan and AIDS,” p. 231.

<sup>35</sup> *Ibid.*

<sup>36</sup> *Ibid.*

<sup>37</sup> *Ibid.*, p. 232.

<sup>38</sup> Gould, *Moving Politics*, 131.

Larry Kramer, the outspoken co-founder of Gay Men's Health Crisis (GMHC), expressed his outrage at the FDA's slow response to the AIDS crisis and the AIDS service organizations that did not embrace political action to push a better federal response.<sup>39</sup>

While other founders of GMHC argued that they stayed true to their original intent of providing service and care to people with AIDS, Larry Kramer wanted a more political response grounded in action.<sup>40</sup> Tapping into a longstanding tradition, ACT UP members embraced zap actions, the purpose of which was to “zap” or “jolt” people into action through the combination of nonviolent civil disobedience and campy humor.<sup>41</sup> The 1987 *Bowers v. Hardwick* decision proved to be a catalyst that united lesbian and gay communities and taught them the value of confrontational zap action.<sup>42</sup> ACT UP, however, added their sense of rage and anger to their zaps. Kramer's rage was rooted in the very real fear that inaction would lead to mass death due to AIDS. For example, when Kramer took on his former organization Gay Men's Health Crisis in 1987, he emphasized, “The worst years of the AIDS pandemic lie ahead of us... *There are millions of us yet to die.*”<sup>43</sup> Kramer believed activists had to expose the slow federal response to AIDS in order to get people living with the disease the treatment they needed.

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<sup>39</sup> Brier, *Infectious Ideas*, 160.

<sup>40</sup> Gould, *Moving Politics*, 247.

<sup>41</sup> In *Acts of Gaiety: LGBT Performance and the Politics of Pleasure*, Sara Werner dates zap actions back to the Youth International Party (Yippies) who used the media in combination with direct action. Described as a “merry group of pranksters,” Yippies taught the New Left how to combine entertainment and protest through zaps, p. 79-80. In *Out for Good: The Struggle to Build a Gay Rights Movement in America*, Dudley Clendinen and Adam Nagourney explain that members of the gay liberation movement group Gay Activist Alliance took up the mantle of zap actions, introducing the founders of ACT UP to the idea, p. 543.

<sup>42</sup> Gould, *Moving Politics*, 122.

<sup>43</sup> *Ibid.*, p. 147.

Kramer argued that activists had to get people with AIDS access to drugs (other than the new and dangerous AZT) by speeding up the drug approval process.<sup>44</sup> However, as committees with different focuses formed in the group, members challenged Kramer and ACT UP's original goal of getting "drugs into bodies" and instead fought for a broader definition of treatment.<sup>45</sup> Members routinely pushed ACT UP to expand its boundaries to better serve the majority of people with AIDS, including people of color and women.<sup>46</sup>

Over two hundred people attended ACT UP's first meeting, drawn from New York's various gay and lesbian groups. Comprised of mostly college-educated white gay men who held professional jobs, men and women in ACT UP activists were "united in anger" and with the encouragement of leading and founding member Larry Kramer, channeled their grief over the AIDS crisis into rage towards the mishandling of the crisis. Activists' rage, Kramer argued, would fuel their civil disobedience and garner enough public attention to enact real change for people with AIDS. ACT UP did have a smaller contingency of lesbians, artists, people of color, and heterosexuals.<sup>47</sup> These members of ACT UP, in particular, consistently challenged each other over which issues should earn the most attention and funding, while also combatting the racism and sexism that was present in the group.<sup>48</sup>

Women members of ACT UP, who made up nearly a quarter of the group by 1990, expanded the focus of the mostly white male group by bringing feminism into ACT

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<sup>44</sup> Carroll, *Mobilizing New York*, p. 162.

<sup>45</sup> Ibid., p. 168.

<sup>46</sup> Brier, *Infectious Ideas*, p. 162.

<sup>47</sup> Carroll, *Mobilizing New York*, 144.

<sup>48</sup> Ibid., p. 158.

UP by uniting over their shared anger.<sup>49</sup> Most of these women were lesbians and had experiences in previous movements, while a few women had worked as sex workers, used intravenous drugs, or were homeless at some point in their lives. Many women in ACT UP had long histories of political activism rooted in the women's movement of the 1960s and 1970s and were dedicated feminist activists. When these women sought to pursue their activism in male groups like ACT UP, they had to fight for space for their feminist understanding of the AIDS crisis and actions that would benefit women living with HIV/AIDS. Advocates of a more feminist understanding of AIDS embraced a worldview in which multiple forms of oppression interacted, rather than acted as distinct overlapping oppressive forces, women AIDS activists centered the needs of, and drew connections between, women of different races, classes, and sexualities in ACT UP.

Women in the AIDS movement argued that factors such as a woman's race, her class position, or her risky behaviors contributed to women's overall exclusion from the AIDS narrative and health care. They argued that women of color with AIDS made up the largest groups of women with the disease because they experienced forms of overlapping exclusion due to misinformation about AIDS, inaccessibility of treatment, and withholding of benefits.<sup>50</sup> In fact, by the early 1991, AIDS was one of the leading causes of death in premenopausal women of color.<sup>51</sup> Activists pointed to the CDC's statistic that seventy three percent of women with AIDS were women of color living in

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<sup>49</sup> Ibid.

<sup>50</sup> Subjects, Federal, Jan.-Dec. 1991. January-December, 1991. MS ACT UP: The AIDS Coalition to Unleash Power: Series VIII. Subjects Box 84, Folder 8. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tPMD1>. Accessed 4 Feb. 2018.

<sup>51</sup> Ibid.

urban areas, with fifty-seven percent of them transmitted AIDS through intravenous drug use, while thirty-two percent acquired the disease through heterosexual sex.<sup>52</sup> The mostly white women in ACT UP argued that as poor women of color, many women with AIDS suffered from substandard medical care already, and the sexism of the medical industry prevented doctors from making accurate diagnoses even when women could gain access to routine medical care. In making this argument, women in ACT UP built their argument upon a long tradition of black women who had paved the way in describing multiple forms of simultaneous oppression. Black women had long argued that they experienced a unique stigma as black women as people of color, as women, and for some, women living in poverty.

The idea that black women experienced heightened oppression can be seen as early as Sojourner Truth's 1851 critical question, "Ain't I A Woman?"<sup>53</sup> Truth's speech had been recounted several ways in the decades after, so there is some controversy how accurately her speech has been remembered. However, whether or not she did give the speech and it has or has not been remembered accurately, Truth became famous for the idea.<sup>54</sup> She asked her white audience at the women's rights convention if she, too, as a black woman would receive the same increased rights for which white women and abolitionists advocated. Black women continued to build upon Truth's idea into the twentieth century. In 1904, Mary Church Terrell, the first president of the National Association of Colored Women wrote, "Not only are colored women... handicapped on

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<sup>52</sup> Ibid.

<sup>53</sup> Sojourner Truth, "Ain't I A Woman?" (Women's Convention, Akron, Ohio, 1851).

<sup>54</sup> "Sojourner Truth," Women's Rights National Historical Park, accessed Feb. 9, 2018. <https://www.nps.gov/wori/learn/historyculture/sojourner-truth.htm>.

account of their sex, but they are almost everywhere baffled and mocked because of their race. Not only because they are women, but because they are colored women.”<sup>55</sup> And as historian Denise Lynn shows, in the 1940s Claudia Jones argued that the “convergence of race and class” were “distinctive in black women’s oppression” as she demanded for more inclusion within Communist Party.<sup>56</sup> Similarly called “double jeopardy” in 1969 by Frances M. Beal, the argument that black women faced additional oppression as black women continued to develop in the 1970s.<sup>57</sup> When the AIDS crisis hit women of color at higher rates than any other group of women, women in the AIDS movement, who would have been familiar with Beal’s work, understood that they needed to address larger issues of racial inequality and poverty, in addition to sexism.

At a critical moment in black women’s activism in 1977, the Combahee River Collective of Black feminists published what has become an essential statement explaining how they came to see racism, sexism, and class as simultaneously oppressing black women. Arguing “the major systems of oppression are interlocking,” the Combahee River Collective explained that white men have always seen black women as adversaries to both patriarchy and white supremacy.<sup>58</sup> Black women developed an “awareness of how their sexual identity combined with their racial identity” made their

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<sup>55</sup> Deborah K. King, “Multiple Jeopardy, Multiple Consciousness: The Context of a Black Feminist Ideology,” *Signs* 14, no. 1 (Autumn 1988): 42.

<sup>56</sup> Denise Lynn, “Socialist Feminism and Triple Oppression: Claudia Jones and African American Women in American Communism,” *Journal for the Study of Radicalism* 8, no. 2 (Fall 2014): 7.

<sup>57</sup> Frances M. Beale, “Double Jeopardy: To Be Black and Female” (Third World Women’s Alliance, 1969).

<sup>58</sup> Demita Frazier, Beverly Smith, and Barbara Smith, “The Combahee River Collective Statement: Black Feminist Organizing in the Seventies and Eighties” (Combahee River Collective, 1977), 1.

struggles unique.<sup>59</sup> Their combined “anti-racist and anti-sexist position” initially allowed black women to organize politically against race-based, class-based, and sex-based oppression that they “experienced simultaneously.”<sup>60</sup> However, after coming together as a collective and learning about one another’s similar experiences, the women of the Combahee River Collective also organized against the “heterosexism and economic oppression under capitalism” that devalued their lives.<sup>61</sup> By vowing to use a “collective process and a nonhierarchical distribution of power,” the members of the Collective broke away from other movements. They felt excluded from the white-dominated branches of the feminist movement and the male-dominated Black Power movement and vowed to create their own group to organize around their overlapping identities as women, people of color, and for some, poor people.<sup>62</sup>

As the AIDS crisis hit communities of color, historian Evelyn Hammonds built upon the analysis offered by the women of the Combahee Collective and in 1987, argued that activists needed to combine anti-racism, with anti-homophobia and anti-sexism to best reach the diverse population of people with HIV/AIDS. In the middle of the crisis, Hammonds recognized the detrimental effects of categorizing AIDS as a white gay man’s disease had for African Americans. The result, she argued, was that both the white and black media neglected to cover the disease adequately. White media outlets tended to ignore the growing rates of AIDS amongst African Americans and Latino-Americans, a symptom of their retrograde “color-blindness.” While an attempt at “progress” by not

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<sup>59</sup> Ibid., p. 2.

<sup>60</sup> Ibid., p. 3.

<sup>61</sup> Ibid.

<sup>62</sup> Ibid., p. 11.



“seeing” race, Hammonds argued, the white media ignored that “race remains a reality in this society.”<sup>63</sup> At the same time, when the white media did cover the disease in populations of color, they implicitly portrayed it as a risk to white, middle class heterosexuals while ignoring that ninety percent of heterosexuals with AIDS were people of color.<sup>64</sup> And in at least one case in a 1987 *Atlantic Monthly* piece, journalist Kate Leishman explicitly cast black or Latinx people with AIDS as “others,” whose lack of self-control in terms of sexual relations or drug use, led to their HIV infection.<sup>65</sup> Meanwhile, one of the reasons the black media did not cover the disease, Hammonds argued, was because AIDS reinforced historical stereotypes of black people as diseased and deviant.<sup>66</sup> “The black community’s relative silence about AIDS is in part also a response to this historical association of blacks, disease, and deviance,” she wrote.<sup>67</sup> Historically, she noted, doctors used “‘objective’ science” to justify both slavery and medical experiments on African Americans. This history, combined with the pressure of respectability politics, led African Americans to embrace sexual conservatism that led “the black media [to] avoid public discussion of sexual behavior and other ‘deviant’ behavior like drug use.”<sup>68</sup> In those articles that did cover AIDS in the black community, contributors to *Ebony* and *Essence* magazines focused on individuals’ behaviors, like men who had sex with other men but did not consider themselves homosexual, rather than examining how poor education about sex and sexuality in black communities

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<sup>63</sup> Evelyn Hammonds, “Race, Sex, and AIDS: The Construction of ‘Other,’” *Radical America* 20, no. 6 (October 6, 1987): 29.

<sup>64</sup> *Ibid.*, p. 34.

<sup>65</sup> *Ibid.*

<sup>66</sup> *Ibid.*, p. 30.

<sup>67</sup> *Ibid.*, p. 29.

<sup>68</sup> *Ibid.*, p. 31.

contributed to the crisis.<sup>69</sup> Furthermore, both the white and black media pushed the problematic idea that with sexual abstinence and a return to “traditional values” people could save themselves from the disease.<sup>70</sup> In response, Hammonds called for a “progressive, feminist, and gay” movement that built upon the work “they [had] done on sexuality and sexual politics” to dismantle homophobia and sexism in both the government and society at large to fight against AIDS, both practically through education and politically through activism.<sup>71</sup> Hammonds reflected a growing trend to acknowledge a more complicated picture of the AIDS crisis. She argued that there was more to the AIDS crisis than homophobia: racism too played a role in how media and people viewed the disease.<sup>72</sup>

Many women in ACT UP, who may have been familiar with Hammonds’ call, attempted to build a coalition similar to the one Hammonds suggested. In this process, women in ACT UP seemed to follow in the historical footsteps of the women activists of the 1960s and 1970s women’s movements for health care and welfare benefits. The women’s health movement began, according to historian Ruth Rosen, in the late 1960s as women held workshops in bookstores, homes, and other private meeting areas across the

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<sup>69</sup> Ibid., p. 32.

<sup>70</sup> Ibid., p. 33.

<sup>71</sup> Ibid., 36.

<sup>72</sup> This whitewashing, or as historian Sarah Schulman labels “gentrifying,” of the AIDS narrative has been continually perpetuated. In Schulman’s memoir, *Gentrification of the Mind: Witness to a Lost Imagination* (Berkeley: University Of California, 2013), she argues that the consequences of the AIDS crisis has fueled the literal gentrification of cities and metaphorical gentrification of the mind as histories of AIDS paint change as inevitable instead of the results of the blood, sweat, and tears of AIDS activists. In her attempt to “degentrify” the story of the AIDS that has been perpetuated by gay and lesbian survivors, Schulman reminds readers that change was only possible thanks to the work of activists.

country to educate other women on their mental and physical health—and perhaps more importantly, their role in their own health.<sup>73</sup> As these health workshops blossomed across the country, one feminist group began to collect the information taught in these workshops. As historian Wendy Kline shows, when the Boston Women’s Health Collective published *Our Bodies, Ourselves* in 1973, they argued that women could unify across “barriers of race, color, income, and class,” through a greater familiarity of their “womanhood from the inside out.”<sup>74</sup> For the Women’s Health Collective, understanding womanhood meant not only scientific knowledge female body, but also an awareness that woman were all connected through their experiences as owners of female bodies. However, this type of language alienated women of color by attempting to “create a universalist notion of shared oppression.” Such a view, critics argued, failed to recognize the unique needs of women’s different experiences, including the needs of lesbians.<sup>75</sup> ACT UP activists, many of who came from the women’s health movement and were lesbians themselves, sought to make sure that what they believed was the marginalization of women of color and lesbians was not replicated in the AIDS movement. And because marginalized women had the highest risks of contracting HIV/AIDS, activists believed it was important to understand how factors of race and sexuality prevented women from accessing AIDS education and health care.

While women in ACT UP believed the women of color and lesbians were left out of the women’s movement, it is important to note that historians have uncovered the

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<sup>73</sup> Ruth Rosen, *The World Split Open: How the Modern Women’s Movement Changed America* (New York, NY: Penguin Books, 2000), 176.

<sup>74</sup> Wendy Kline, *Bodies of Knowledge: Sexuality, Reproduction, and Women’s Health in the Second Wave* (Chicago: The University of Chicago Press, 2010), 3.

<sup>75</sup> Kline, *Bodies of Knowledge*, 4.

many ways that marginalized women contributed to and helped shape the movement. Sandra Morgen pointed to the ways that women of color, welfare recipients, antiwar activists also participated in the women's health movement. Morgen demonstrates that many grassroots activists shaped the movement from 1969 to 1990, each creating a revolution that reformed both women's health care and political activism. Stemming from her own experience working in a women's clinic, Morgen argues that feminist health clinics, and the women who practiced there, demanded better health care, better access to knowledge, and more women health practitioners who better understood women's bodies.<sup>76</sup> The work of the women in the women's health movement, Morgen demonstrates, resulted in dramatic cultural, social, and political shifts that would also shape the AIDS movement, amongst others. Based on oral histories, *Into Our Own Hands* returns focus to the individual actors, and not just white, privileged heterosexual women, who fought in the movement for better women's health care.<sup>77</sup>

Jennifer Nelson further developed Sandra Morgen's argument, demonstrating that multiracial women from different activist backgrounds transformed women's health across the country. Nelson demonstrates that activists in the civil right movement, New Left, and feminist movements converged in the 1960s to 1990s to change the way Americans thought about health and health care. Rooting the women's health movement not in the Women's Liberation movement, but in earlier civil rights and New Left movements, Nelson argues that women, even those outside of the major cities like New York and Boston, held on to the revolutionary ideas of the 1960s and further developed

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<sup>76</sup> Sandra Morgen, *Into Our Own Hands: The Women's Health Movement in the United States, 1969-1990* (New Brunswick, N.J: Rutgers University Press, 2002), x.

<sup>77</sup> Ibid., p. xi-xii.

them through the 1990s. Nelson demonstrates that women of color in Atlanta, for example, formed an AIDS outreach program for other women of color in order to educate women about their potential risks of contracting HIV/AIDS and successful barrier methods to prevent transmission.<sup>78</sup> And further challenging the idea that white women were unresponsive to the needs of women of color, Nelson shows that the National Organization of Women (NOW) attempted to incorporate a more racially inclusive message by hiring Loretta Ross as the Director of Women of Color Programs, who fought for the inclusion of black women in the women's health movement of the 1970s. Ross's own experiences with racism, sexual assault, and reproductive restrictions allowed her to incorporate the specific issues of race, class, and black women's personal experiences into NOW's platform.<sup>79</sup> Women in the AIDS movement too followed in this pattern and tried to expand their understanding of how HIV/AIDS affected women of color by organizing with HIV positive women.

Historian Tamar Carroll connected AIDS activism to the welfare rights movement in her examination of the welfare rights movement of postwar New York City, arguing that both welfare rights activists and activists in the AIDS movement articulated an "inclusive, egalitarian" view of citizenship in order to mobilize poor people to demand their entitled benefits.<sup>80</sup> Carroll shows that ACT UP's grassroots activism, zap action through boycotts, sit-ins, strikes, and mass demonstrations followed in the tradition of previous New York City activists, who demanded both that the state include the right to

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<sup>78</sup> Jennifer Nelson, *More Than Medicine: A History of the Feminist Women's Health Movement* (New York: New York University Press, 2015), p. 165.

<sup>79</sup> Ibid., p 168.

<sup>80</sup> Tamar W. Carroll, *Mobilizing New York: AIDS, Antipoverty, and Feminist Activism* (Chapel Hill: University of North Carolina Press, 2014), 20.

good health and filled in the gaps in their community programs that resulted from city-wide budget cuts. Carroll highlights how women connected the AIDS movement to the reproductive rights movement in the 1980s to argue that ACT UP, and the backdrop of New York City, provided a space for women to build coalitions with gay men while simultaneously advocating for women's issues.

While Carroll directly connected the AIDS movement to other New York City welfare activism, the women in ACT UP followed in the patterns of national welfare rights activists who both recognized the role that racism played in kept women from their welfare benefits and created multiracial coalitions to fight that racism. Annelise Orleck, for example, demonstrated that black mothers on welfare in West Las Vegas in the early 1970s formed a multiracial coalition of mothers, politicians, lawyers, priests, and celebrities as they created resources like job training, day care, and a federally-funded medical clinic.<sup>81</sup> Premilla Nadasen, too, shows that other women, like the white, Latina, Native, and black mothers of the National Welfare Rights Organization (NWRO), tackled the association of welfare with blackness, arguing in 1972 that welfare was not a "black problem," but rather an economic one, or a "green problem."<sup>82</sup> Mothers of the NWRO united over their shared experiences of class-based oppression from a welfare system enacted through caseworkers while ultimately placing racism as the root of all women's problems with accessing welfare.<sup>83</sup> Furthermore Marisa Chappell shows that even

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<sup>81</sup> Annelise Orleck, *Storming Caesars Palace: How Black Mothers Fought Their Own War on Poverty* (Boston: Beacon Press, 2005), 3.

<sup>82</sup> Premilla Nadasen, "'Welfare's a Green Problem': Cross-Race Coalitions in Welfare Rights Organizing," in *Women's Activism and "Second Wave" Feminism: Transnational Histories* (New York, NY: Bloomsbury Academic, 2017), 192.

<sup>83</sup> Ibid.

organizations comprised of mostly white women participated in this welfare rights movement. In her examination of the traditional women's group League of Women Voters, she found that the group called for "fundamental income redistribution" to address the issues of racial inequality and poverty in 1971.<sup>84</sup> In a similar way, the mostly white women of ACT UP tried to form around the understanding that racism prevented women of all races from accessing treatment and education.

Existing histories of women activists then, provide an important foundation for understanding the complexity of the process of women's coalition building and the resulting conflicts that caused many of the women in the AIDS movement to leave ACT UP. As they developed an original analysis of the times, women in ACT UP argued that racism, classism, sexism, and heteronormativity all contributed to the neglect of women with AIDS. However, in response to the continued negligence of women with AIDS into the 1990s, from both inside ACT UP and outside through the government's inaction, most women left ACT UP and they took their ideas to new spaces. Women in the AIDS movement too the traditional narrative of the AIDS epidemic by creating space for themselves within ACT UP and outside as they moved beyond the group. Their activism, then, resists the narrative that activism ceased after the fractures of the 1970s. In fact, women in ACT UP learned a great deal from the successes and failures from the activism of the 1960s and 1970s and organized in response to previous movements.<sup>85</sup>

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<sup>84</sup> Ibid.

<sup>85</sup> Jennifer Brier and Tamar Carroll established that the members of ACT UP consciously responded to the successes and failures of the movements of the 1970s, particularly the gay liberation and women's health movements.

This pattern was not unique to postwar activism. The story of AIDS activism, then contributes to Richard Iton's argument that the 1970s and 1980s were not a retrenchment from public engagement, but rather a transition in leadership to marginalized people. Iton argues that for African Americans, this fracturing, or what he labels as reordering, in the 1970s provided space for women, gays and lesbians, and people in poverty to develop politically.<sup>86</sup> These "marginalized constituencies within the black community" mobilized right as the traditional narrative of the 1970s says the "black public sphere" crumbled.<sup>87</sup> The fact that the Combahee River Collective, for one, organized in spite of this "collapse," Iton argues, demonstrates that there was no wholesale collapse of the common public sphere. He further argues that historians' insistence on pushing this narrative erases the contributions of the more marginalized groups of black women, black LGBTQ+ people, and black people with low incomes.<sup>88</sup> Iton demonstrates that activists in the 1990s did not simply fade into the background. Instead women and other marginalized groups created new places for their activism.

Similarly, Daniel T. Rodgers argues that intense social debates over American identity and purpose after World War II resulted in a fracturing of ideas and identity in the 1970s. Before the war, he argues, Americans participated in a type of consolidation and unification of ideas and language, but during the 1970s through the 1990s Americans

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<sup>86</sup> In her 2003 book *Separate Roads to Feminism*, Benita Roth argued something similar to Iton. She examines how black women, Chicana women, and white women came to their feminism to form distinct movements that at times, worked together and also challenged one another. Instead of viewing the feminist movements of the 1960s and 1970s as fractured along lines of race and class, Roth suggests that women created (and contested) alliances with one another.

<sup>87</sup> Richard Iton, *In Search of the Black Fantastic: Politics and Popular Culture in the Post-Civil Rights Era* (Oxford: Oxford University Press, 2010), 20.

<sup>88</sup> Ibid.



grew unsure of their national purpose. This break down in ideas, language, and sense of identity threatened institutions and solidarities.<sup>89</sup> In response to this disaggregation, people tried to make sense of a country unsure of its future and divided by economics, class, race, gender—and their own ideas about those distinctions. For example, gender roles changed dramatically during the postwar period and by the 1970s, feminists were embroiled in internal divisions based on women’s differences, like class, race, and sexuality, while trying to establish their similarities as women.<sup>90</sup> During the AIDS crisis, Rodgers argues, women and gay men banded together to fight the idea that deviancy, as opposed to “normal” sexual behavior, led to the AIDS crisis.<sup>91</sup> In this way, activists fought against the disaggregation that plagued 1970s and 1980s. Women in ACT UP took a similar path. Activists came together over an urgent and a shared understanding of how racism and sexism harmed women with AIDS. However, conflicts over how these realities factored into ACT UP’s activism splintered the group and many women left the group. Women in the AIDS movement, thus, left ACT UP and participated in a fragmentation process that spread their ideas to new and old fields, like service organizations, the law, art, media, and academia.

Even after leaving ACT UP, women AIDS activists continued to work in AIDS, using a language of double or triple jeopardy to explain women’s subjugation and empowerment in ongoing efforts to counter the ways that race, gender, class, sexuality, and an AIDS diagnosis could threaten women’s health by making them socially and politically invisible. Through their activism, women forced changes in the AIDS

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<sup>89</sup> Daniel T. Rodgers, *Age of Fracture* (Cambridge, MA: Harvard Univ. Press, 2012), 3.

<sup>90</sup> Ibid., p. 147.

<sup>91</sup> Ibid., p. 162.

narrative in large part by bringing more voices into the movement. Movement-changing ideas came from women from a wide variety of backgrounds, including white middle-class career activists, professional women with expert knowledge, and women of different classes and racial and ethnic groups inspired to take action by their firsthand experiences with AIDS. Career activists who had participated in New Left or progressive movements brought an understanding of systemic oppression, a language to describe that oppression, and tactics that had proven successful in the past to fight oppression into AIDS activism. Professionals brought expert knowledge from their careers as nurses and lawyers, and they helped enact more permanent change through their connections to the medical and legal fields. Working-class women and women in poverty who lived a kind of politics of survival in which their everyday lives were threatened by the AIDS crisis, individually and collectively developed deeper understandings of the kinds of outreach women with AIDS really needed. ACT UP brought these histories of activism together by providing a moment of convergence for women of a variety of backgrounds and understandings about race, gender, class, sexuality, and AIDS.

Women in the AIDS movement grounded their activism and advocacy in the lessons of past movements and their belief that women of color, particularly poor women of color, faced barriers to care. Moreover, they created a new wing of social activism that was itself internally diverse—including professional women's expert advocacy, career activists, and poor women with AIDS. The diversity of feminist AIDS activism caused friction in the movement, but it was a friction that drove a process of social learning that informed increasingly refined effective movement strategies. Women thus redefined AIDS activism to fight for the needs of people who did not fit the dominant image of the

“real” victims of the epidemic, white gay men. And, in the biggest picture, they provided an example, however complex and imperfect, of a movement that built strategy at the ground level and empowered leaders to engage in progressively more effective tactical attacks upon women’s exclusion from justice in health care.

This thesis uses activist literature, such as pamphlets, fliers, internal documents from ACT UP and GMHC, as well as oral histories conducted by surviving ACT UP member and historian Sarah Schulman in order to preserve members’ recollections and feelings about their time in the organization. Schulman, funded by Ford Foundation and assisted by former ACT UP member and filmmaker Jim Hubbard, began to conduct these oral histories in her subjects’ homes from December of 2002 through 2015.<sup>92</sup>

Interviewing nearly two hundred surviving members, Schulman worked to “present comprehensive... pictures” of the “men and women of all races and classes” who “transformed entrenched cultural ideas” and “achieved concrete changes” in the fields of law, medicine, art, and political organizing.<sup>93</sup> In all, Schuman has collected 186 interviews, the majority of which are white members who either did not have the disease themselves or had not succumbed to it at the time of their interview.

Through an analysis of Schulman’s oral histories, I demonstrate that ACT UP’s activists believed that they were some of the country’s foremost and most successful AIDS activists. Members of ACT UP recalled creating a much more diverse and effective coalition than history shows. I propose that this is a natural response to the conservative

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<sup>92</sup> Sarah Schulman, “ACT UP Oral History Project Bios,” <http://www.actuporalhistory.org/about/bios.html>, accessed Feb. 20, 2018.

<sup>93</sup> Sarah Schulman, “ACT UP Oral History Project About,” <http://www.actuporalhistory.org/index1.html>, accessed Feb. 20, 2018.

era in which they organized. During the Reagan administration, there was no shared national interest in responding to the AIDS crisis, despite the very real threat the AIDS posed to Americans. Historian Deborah Gould, for example, compares the federal response between Legionnaires' disease and AIDS. In 1976, when Legionnaires' disease killed thirty-four people, the CDC spent nine million dollars on research. Meanwhile, when over two hundred people died from AIDS in the first year of the epidemic, the CDC spent only one million dollars.<sup>94</sup> Likewise, compared to the national response to discovering and administering the polio vaccination, it was the AIDS crisis resulted in very little federal action. In response to overwhelming apathy, activists had to unify a shaky coalition of people with AIDS, most of whom in the organization were white gay men, white lesbians, and a much smaller contingent of people of color. As historian Dan Royles pointed out, ACT UP activists were disobedient, unpopular, loud, and disruptive. These characteristics, Royles argues, were necessary in the face of an uncaring and unresponsive society that blamed people with AIDS for their illnesses.<sup>95</sup> With that in mind, it is understandable that members of ACT UP exhibit a type of vanguardism in which they believed the militancy of their actions were justified by the complacency around them.

ACT UP activists' sense of vanguardism was also encouraged by the politics of New York City. As Tamar Carroll demonstrates, 1980s New York City was still recovering from the economic crises of the 1970s. Most importantly, that recovery was

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<sup>94</sup> Deborah B. Gould, *Moving Politics: Emotion and Act Up's Fight Against AIDS* (Chicago: The University of Chicago Press, 2009), 50.

<sup>95</sup> Jonathon Bell et al., "Interchange: HIV/AIDS and U.S. History," *The Journal of American History* 104, no. 2 (September 2017): 448.

entirely uneven and the poverty rate of New York City was twice the national average.<sup>96</sup> Gentrification displaced poor and working class residents while creating an epidemic of homelessness in favor of new developments for the city's financial workers, led by Mayor Ed Koch's "pro-investor" policies.<sup>97</sup> Meanwhile, Mayor Koch led the efforts to "clean up" the city by rounding up sex workers, "criminals and hustlers."<sup>98</sup> Reminiscent of his earlier promise to remove the "bums, degenerates, and homosexuals" from Greenwich Village, Koch's conservative policies villainized many of the people who would become members of ACT UP.<sup>99</sup> In fact, women in ACT UP believed they organized in direct opposition to Mayor Koch.<sup>100</sup>

The majority of the women spotlighted in this thesis were the leaders of either the Women's Caucus or the Women's Action Committee, like Maxine Wolfe, Marion Banzhaf, and Maria Maggenti, and had experience in previous political movements. Thus, they were outspoken about their desires to adapt ACT UP to help women, particularly women of color. Other women, like Catherine Saalfeld, Zoe Leonard, and Jean Carlomusto were prominent feminist members of ACT UP who both participated in the women's groups and collaborated with men in the group to produce art. A smaller contingent of the women in this thesis were professionals, like Terry McGovern and

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<sup>96</sup> Carroll, *Mobilizing New York*, p. 131.

<sup>97</sup> Ibid.

<sup>98</sup> Selwyn Raab, "Koch Gets Plan for Cleanup of Times Sq. by 1980," *New York Times*, July 3, 1978, p. 23.

<sup>99</sup> Robert O. Self, *All in the Family: The Realignment of American Democracy since the 1960s*, (New York: Hill and Wang, 2012), 178.

<sup>100</sup> Zoe Leonard, transcript of an oral history conducted in 2010 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2010), <http://www.actuporalhistory.org/interviews/images/leonard.pdf>, accessed June 26, 2017, 27.

Polly Thistlethwaite, who collaborated with ACT UP through their careers. The common factor linking each of these women was their priority to advocate for women with AIDS above all else. However, these histories are limited in nature. Collected after most of the women in ACT UP with AIDS had already died, the women the women represented in these histories did not have HIV/AIDS, and are white and college-educated, with considerable racial and class privilege.

The women in ACT UP who had HIV/AIDS, like Katrina Haslip and Iris De La Cruz, died in the 1990s. While Sarah Schulman asks living ACT UP members about those women in her interviews, it is crucial to note that historians do not have the same kind of access to their thoughts and experiences as we do surviving members. To uncover the motivations of the women who have since passed from HIV/AIDS, this thesis relies on their own writing, in addition to the memories' of others. Despite these shortcomings, Schulman's oral histories are fundamental to my interpretation of women's motivations and life experiences, as no other source base get at their personal thoughts on ACT UP. However, these histories were collected long after members' times in ACT UP and occasionally, members contradict and challenge one another's recollections. Therefore, in addition to relying on oral histories, this thesis uses popular media publications from both the gay and straight media and foundational secondary works on ACT UP.

Activists routinely submitted articles to predominantly gay newspapers and magazines, as they used LGBT print media to facilitate their activism by publishing articles about the group and distributing upcoming protest locations. Therefore, I use articles from the *Village Voice*, *New York Native*, and *Washington Blade* alongside other popular nationally-read newspapers that reported on ACT UP such as the *New York*

*Times*, *Washington Post*, and *Newsday*. Activists also created their own works, from letters to the editor, videos, art, and academic journal articles that provide insight on their goals and histories. Lastly, this thesis builds upon the books by Jennifer Brier and Tamar Carroll who first studied the important role that women played in ACT UP. I build upon these histories and argue that the women in ACT UP, who converged in the group from a variety of backgrounds, purposefully centered the needs of lesbians, women of color, and women living in poverty as a response to their feelings of exclusion from previous movements. This process of convergence, then, created conflict within the group that resulted in a diaspora of sorts; women left ACT UP for new spaces, but stayed true to their convictions that there was a direct and intersecting relationship between poverty, race, gender, sexuality, and access to health care and health education that left marginalized women invisible and vulnerable.

This thesis proceeds thematically and chronologically to demonstrate how activists came to their belief that a racially inclusive and sex-positive feminism could best address the needs of women with AIDS and how this understanding guided both their activist and service work in the AIDS epidemic. Building upon the foundations of Jennifer Brier and Tamar Carroll, this thesis demonstrates women in ACT UP's commitment to their understanding of triple jeopardy long after ACT UP fractured. The second chapter traces how ACT UP's first women worked within the group to provide the residents of New York City with AIDS and safer sex information from 1987 to 1988. The second chapter shows how, with the influence of new members in ACT UP, women experimented with their activism, through different forms of action and a more refined focuses on changing federal policy, demanded that the medical industry provide women

with AIDS with better, more meaningful care, and challenged federal agencies for discriminating against women with AIDS from 1988 to 1990. During this time, women further developed their political consciences and ideas of feminism, while they participated in zap actions, demonstrations, and sit-ins. However, working within male-dominated organizations did not provide some women with opportunities to enact the kind of change they desired.

Therefore, the last chapter examines how, because ACT UP became too divided, too professionalized, and remained too focused on men, women moved beyond the group as early as 1988. Instead, they created new organizations or collaborated with smaller, collective groups made up of women who centered the needs of marginalized women rather than centering men's needs and considering women only on the periphery. Through their work with these groups in the 1990s, some AIDS activists provided education while connecting women with safe housing, transportation, child care, or legal counsel which enacted real and immediate change in the lives of women living with AIDS. Other women turned to art and media to express their grief and continue their activism outside of ACT UP. They created media that featured people with AIDS, gay men and lesbians, and other marginalized people in order to correct poor representations and bring peoples' stories to light. Finally, other women from ACT UP entered, or returned to, academia and wrote articles in which they explored how heterosexism, sexism, and racism hindered women's visibility, health care, and education. Their stories teach us that the combination of both increased social and political awareness about AIDS in women through demonstration and protest and service-oriented care work to



meet the immediate necessities of women in need, some AIDS activists enacted both social and political change for women with AIDS.

## II. CONVERGENCE

During the AIDS crisis, women's AIDS activism evolved through a process of individual and collective learning that allowed women to build coalitions and expand the focus of AIDS activist groups to include women's experiences and perspectives. In key moments, women challenged the media's portrayal of AIDS as a male disease, created resources for women living with AIDS, challenged the medical industry's exclusion of women from clinical drug trials, and exposed the government's discrimination in distributing federal benefits. In the first year of ACT UP's existence, women focused primarily on encouraging sex-positive safer sex practices that encouraged women and men to use protection without losing sight of the eroticism of sex. Some of the first female members found ACT UP through their own political activism, either in AIDS work or other movements, and connected ACT UP's activism with their own passions.

Rebecca Cole, a white recent Northwestern graduate and actress in Chicago, experienced her first loss to Gay Related Immune Disorder (GRID) after her friend and former cast member David Garrett died. She knew him as "the healthiest, most robust, amazing guy," but after he moved to Los Angeles to pursue acting, Garrett died from the flu in 1981.<sup>1</sup> She was shocked and devastated to learn that "this gorgeous, black, magnificent, muscle-bound, healthy-as-an-ox fighter" died from something as small as

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<sup>1</sup> Rebecca Cole, transcript of an oral history conducted in 2008 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2008), <http://www.actuporalhistory.org/interviews/images/cole.pdf>, accessed December 06, 2017, 10-11.

the flu.<sup>2</sup> When news of GRID spread through the media, Cole connected Garrett's death to this mysterious new illness that was killing gay men.<sup>3</sup> So when a cast member told Cole that he applied to start the Center for Disease Control's National AIDS Hotline to direct callers towards resources rather than inundate the CDC's receptionist with questioning calls, Cole jumped at the opportunity to volunteer.<sup>4</sup>

Cole turned to ACT UP after working at the Hotline when she grew frustrated with the CDC's lack of answers for people with AIDS. Her perspective on the disease began to change while working at the hotline. Cole noticed that there was "so much more press was on the men... I realized that there's way more women than anyone's taking about."<sup>5</sup> Callers asked questions that neither Cole nor any volunteers knew the answers to, such as "Could I breast-feed my kids?"<sup>6</sup> When the CDC refused to provide Cole with answers, she turned to ACT UP. "[The CDC] wanted to stop spreading [AIDS]... [I said], well, what about curing it?" Cole asked.<sup>7</sup> When a coworker at the hotline told Cole that a new group called ACT UP was forming to ask that very question, she grew interested. ACT UP was the "opposite of the party line" and "was going to be much more radical."<sup>8</sup> Cole saw that clearly the CDC did not have a workable solution for anyone with AIDS, let alone the desperate women calling into the hotline, and decided to attend a meeting.

Rebecca Cole attended ACT UP's second meeting in March of 1987, even before the group moved from New York University to the Gay and Lesbian Community Center,

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<sup>2</sup> Ibid.

<sup>3</sup> Ibid., p. 15-16.

<sup>4</sup> Ibid., p. 17.

<sup>5</sup> Ibid., p. 23.

<sup>6</sup> Ibid., p. 23.

<sup>7</sup> Ibid., p. 25-26.

<sup>8</sup> Ibid., p. 26.

and was the first female member of the group. Cole found founder Larry Kramer “radical and interesting” and he validated her feelings of “despair and frustration” that she felt working at the National AIDS Hotline.<sup>9</sup> Cole believed, like Kramer, that “playing it safe” was not going to solve the AIDS crisis.<sup>10</sup> Even when Kramer planned to target the National AIDS Hotline office for a sit-in in ACT UP’s first days of March of 1987, Cole collaborated. ACT UP members Kramer, Gregg Bordowitz, and Mark Simpson timed their sit-in to coincide with one of Cole’s shifts to ensure that someone at the hotline called the police because, according to Cole, “an action is only an action if someone calls the police.”<sup>11</sup> From the beginning, members of ACT UP were committed to zap action, civil disobedience and confrontations with police. And while admittedly ACT UP’s demands were “a little vague,” this action, while it was not a major protest that accrued media attention, it was ACT UP’s first effort to bring awareness to government’s mishandling of the HIV/AIDS crisis.<sup>12</sup>

Larry Kramer’s energy, passion, and embrace of nonhierarchical structure attracted ACT UP’s other female members. Maria Maggenti, a recent Smith graduate and a “feminist, lesbian, loud, passionate person,” attended one of ACT UP’s first meetings because she thought the group sounded feminist by nature. “Unleash power,” she explained, “sounded like a feminist space.”<sup>13</sup> When she arrived, she realized that there

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<sup>9</sup> Ibid., p. 27.

<sup>10</sup> Ibid., p. 27.

<sup>11</sup> Ibid., p. 28.

<sup>12</sup> Ibid., p. 29.

<sup>13</sup> Maria Maggenti, transcript of an oral history conducted in 2003 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2003), <http://www.actuporalhistory.org/interviews/images/maggenti.pdf>, accessed December 06, 2017, 3.

was only one other woman in the group, Rebecca Cole, Maggenti stuck around. She felt intrigued by the men in the group, having come from an “exclusively female environment” at college.<sup>14</sup> ACT UP felt young, unlike many of the other groups who met at the Gay and Lesbian Community Center.<sup>15</sup> Meetings were loud, but orderly because, as Tamar Carroll shows, ACT UP imposed *Robert’s Rules of Order* to keep the meetings as democratic and organized as possible.<sup>16</sup> This allowed anyone in attendance the opportunity to speak if they so wanted. Maggenti loved the atmosphere and thought she had finally found a place to put her “political, emotional energy.”<sup>17</sup> While she had worked as a volunteer at Gay Men’s Health Crisis (GMHC) and at a battered woman’s shelter in Harlem where some of the women had AIDS, Maggenti felt she could best channel her energy into action at ACT UP.<sup>18</sup> She “signed up for every single” one of ACT UP’s six committees—issues, actions, fundraising, outreach, media, and coordinating— and threw her “whole life” into the group.<sup>19</sup>

Feelings of intrigue and optimism made other women, too, return to meetings. One of those people, Amy Bauer, who identified at the time as a young Jewish lesbian, originally came to one of the group’s first meetings in March 1987 in order to recruit other people to participate in a civil disobedience action in response to the 1986 *Bowers v. Hardwick* Supreme Court decision.<sup>20</sup> The decision upheld the state of Georgia’s anti-

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<sup>14</sup> Ibid., p. 2.

<sup>15</sup> Ibid.

<sup>16</sup> Carroll, *Mobilizing New York*, 144.

<sup>17</sup> Maria Maggenti, ACT UP Oral History Project, 3.

<sup>18</sup> Ibid., p. 1.

<sup>19</sup> Ibid., p. 5. See also Brier, *Infectious Ideas*, 161.

<sup>20</sup> While assigned female at birth, Jamie (formerly Amy) Bauer is a transman who uses “they/their” pronouns. Jamie’s gender identity shifted in 1989, two years after joining

sodomy law and Bauer was organizing a protest with many of New York’s gay and lesbian groups.<sup>21</sup> At the meeting, Bauer recalled, Kramer dominated the space, “charging up” the meeting attendees, almost all whom were men.<sup>22</sup> People “just wanted to demonstrate, demonstrate, demonstrate. They would schedule five demonstrations in a week, and then go to all of them.”<sup>23</sup> Bauer, who had an interest in civil disobedience, was “hooked.”<sup>24</sup> As a young adult, Bauer had little interest in activism, but upon graduating with their master’s degree from MIT, Bauer took a job working for the New York Transportation Authority.<sup>25</sup> In New York, Bauer joined the Women’s Pentagon Action, a small group of fifty members who “came together to make connections between war, the patriarchy, women’s oppression, [and] the military industrial complex.”<sup>26</sup> While participating in demonstrations with the Women’s Pentagon Action, Bauer read the works of Barbara Deming, a lifelong peace activist, radical feminist, and lesbian, and

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ACT UP, and they changed their name in 2012. I will heretofore use Jamie’s correct name and pronoun—but for clarity’s sake, it is important to note that articles, interviews, and other sources published before 2012 use the name “Amy.” Jamie Bauer, transcript of an oral history conducted in 2017 by Michelle Esther O’Brien, New York City Trans Oral History Project (New York: New York University, 2017), <https://s3.amazonaws.com/oral-history/transcripts/NYC+TOHP+Transcript+015+Jamie+Bauer.pdf>, accessed March 22, 2018, 23.

<sup>21</sup> Amy Bauer, transcript of an oral history conducted in 2004 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2004), <http://www.actuporalhistory.org/interviews/images/bauer.pdf>, accessed December 06, 2017, 4.

<sup>22</sup> Ibid., p. 25.

<sup>23</sup> Ibid., p. 25.

<sup>24</sup> Ibid., p. 26.

<sup>25</sup> Ibid., p. 12.

<sup>26</sup> Ibid., p. 13.

jumped at the opportunity to travel with the group to the Seneca Women's Peace Encampment.<sup>27</sup>

The Seneca Peace Camp provided Jamie Bauer with their first major training in civil disobedience. The Peace Camp was inspired by the Greenham Common Women's Peace Camp's 1981 protest of nuclear weapons and it brought women together from across the Northeast.<sup>28</sup> Established during the summer of 1983, the Seneca Peace Camp consisted of thousands of women who camped in Seneca, New York practicing civil disobedience. Many of the women at the Peace Camp were older women who were "lifelong political activists" with long histories of practicing civil disobedience.<sup>29</sup> Bauer was in "in awe" of women who had participated in prior movements and thus had a "clear analysis... and understanding of... using non-violence for social change."<sup>30</sup> The histories of the women at the Seneca Peace Camp and in the Women's Pentagon Action inspired Bauer to undergo civil disobedience training. When they heard of the *Bowers v.*

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<sup>27</sup> Barbara Deming and Jane Meyerding, *We Are All Part of One Another: A Barbara Deming Reader* (Philadelphia, PA: New Society Publishers, 1984). In her book *Prisons That Could Not Hold*, Deming introduces herself as a writer and anti-nuclear weapons activist with Quaker roots, who embraced Gandhian nonviolence and worked with Martin Luther King Jr. Deming argued that the civil rights movement and the peace movement, amongst others, were all part of one large movement of respect.

<sup>28</sup> Berenice A. Carroll traces the roots of women's direct action from ancient Greece through the twentieth century, demonstrating that women have long created and participated in peace encampments. Carroll describes that women protesting at the Greenham Common missile base used heavy duty locks to seal the base, wrapped fencing in colorful yarn, and danced atop of the missile silos in "'Women Take Action!' Women's Direct Action and Social Change," *Women's Studies International Forum* 12, no. 1 (1989): 3–24. Margaret L. Laware built on Carroll's argument, pointing to the participants' evolving use of rhetoric and imagery that played with spirituality, women's history, and women's bodies in "Circling the Missiles and Staining Them Red: Feminist Rhetorical Invention and Strategies of Resistance at the Women's Peace Camp at Greenham Common," *NWSA Journal* 16, no. 3 (Autumn 2004): 18–41.

<sup>29</sup> Ibid., p. 21.

<sup>30</sup> Ibid., p. 21.

*Hardwick* decision, Bauer began to plan a demonstration and turned to the brand-new ACT UP for more participants.<sup>31</sup>

Jamie Bauer began attending meetings as the group planned its first major demonstration. In an attempt to gain national media attention, the founding members of ACT UP, including Rebecca Cole and Maria Maggenti, organized their first major demonstration. According to Maggenti, the goal of the demonstration was “to get as much press as possible, and be as disruptive as possible, to try and get people to think about AIDS.”<sup>32</sup> To accomplish this, demonstrators block traffic access to New York City’s financial district near Broadway and Wall Street.<sup>33</sup> As historian Tamar Carroll shows, the purpose of the Wall Street protest was to target the drug companies making money off the high cost of AIDS medications.<sup>34</sup> ACT UP demanded the release of affordable drugs, the establishment of a national policy on AIDS, and a policy to prevent discrimination on the basis of an AIDS diagnosis.<sup>35</sup>

Protestors targeted the various institutions at work on prolonging the AIDS crisis. They burned an effigy of Food and Drug Administrator, Frank Young, as an expression of their anger with the slow drug approval process.<sup>36</sup> Meanwhile, another group of

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<sup>31</sup> Peregrine Schwartz-Shea and Debra D. Burrington’s argue in “Free Riding, Alternative Organization and Cultural Feminism: The Case of Seneca Women’s Peace Camp,” *Women & Politics* 10, no. 3 (1990): 1–37 that the “feminist process” of shared leadership actually made the Seneca Peace Encampment more dysfunctional, as only a small percentage of the larger group did the majority of the work.

<sup>32</sup> Ibid., p. 17.

<sup>33</sup> Frances McMorris, “Gays Protest Lack of Drugs to Wage War Against AIDS,” *New York Daily News*, March 25, 1987, page 7.

<sup>34</sup> Carroll, *Mobilizing New York*, 142.

<sup>35</sup> Jennifer Brier, *Infectious Ideas: U.S. Political Responses to the AIDS Crisis* (Chapel Hill: University of North Carolina Press, 2009), 160.

<sup>36</sup> Ibid., p. 7.



activists staged a “die-in” in front of Trinity Church, one of the largest landowners in New York City. The church was well-known for its incredible wealth, which it had accumulated since its beginning in 1705.<sup>37</sup> In another instance, four other ACT UP members entered the New York Stock Exchange and handcuffed themselves on the floor in order to “delay its opening.”<sup>38</sup> Rebecca Cole remembered how radical, exciting, and for her, the daughter of a stock broker, a little “humiliating.”<sup>39</sup> The demonstration, which lasted from seven o’clock to ten o’clock in the morning, resulted in the arrest of seventeen to nineteen ACT UP members.<sup>40</sup> As Jamie Bauer recalled, activists and police coordinated the arrests beforehand and even signaled to police which members should be arrested with color-coded armbands.<sup>41</sup> It was important for the demonstration to end in the arrest of a few “people with recognition,” rather than the entire group, said Bauer, to ensure press coverage.<sup>42</sup>

The protest had mixed results. Both the FDA and Burroughs Wellcome, the manufacturer of AZT, responded with changes. The FDA announced it would shorten its drug approval process so that people dying from AIDS could potentially get drugs faster. Meanwhile, Burroughs Wellcome reduced the price of AZT from \$10,000 for a year’s

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<sup>37</sup> Diane Henry, “Trinity Church as Landlord,” *New York Times*, February 10, 1982, sec. D23.

<sup>38</sup> Maggenti, ACT UP Oral History Project, 17. Jennifer Brier uncovered the “die-in” aspect of the Wall St. I protest in *Infectious Diseases* p. 160.

<sup>39</sup> Cole, ACT UP Oral History Project, 50.

<sup>40</sup> Accounts differ between activists and media reports. For example, Frances McMorris wrote that seventeen people were arrested, while Maria Maggenti and Jamie Bauer recall that nineteen members were arrested.

<sup>41</sup> Bauer, ACT UP Oral History Project, 25.

<sup>42</sup> Ibid.

supply to \$6,000.<sup>43</sup> According to Tamar Carroll, these successes encouraged ACT UP to continue to target “AIDS profiteers.”<sup>44</sup> However, despite ACT UP members’ hopes, the demonstration received very little media coverage: the *New York Daily News* included a small article on the protest on page seven, while the *New York Times* only described the protest in an article about the increasing public concern about the spread of HIV/AIDS.<sup>45</sup>

However, the demonstration taught the members of ACT UP an important lesson. As Rebecca Cole remembered, the demonstration affirmed to participants that they were on the right side. “There wasn’t an ounce of me that felt like we were on the wrong side. And I could see that every single person watching thought we were on the wrong side. And I knew that someday, they’d know that wasn’t true.”<sup>46</sup> Jamie Bauer, too, felt this sense of encouragement and purpose, but she also believed that her background in civil disobedience could elevate the organization.<sup>47</sup> At first, Bauer explained, they “was very critical” of ACT UP’s style of civil disobedience. They felt that ACT UP’s “celebrity civil disobedience” in which only a few media-friendly members demonstrated that “they didn’t know anything about demonstrating.”<sup>48</sup> With their experience in civil disobedience, Bauer often acted as a marshal or go-between protestors and police. They taught the members of ACT UP not to organize protests with police beforehand and not run away upon seeing police presence, as it left the most vulnerable, like older or sicker

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<sup>43</sup> Carroll, *Mobilizing New York*, 142.

<sup>44</sup> Ibid., p. 143. After this protest, Carroll also argues ACT UP’s trademark “Silence=Death” posters made an impression on New Yorkers after ACT UP members plastered the city with them.

<sup>45</sup> Ronald Sullivan, “AIDS Overtakes Disease of Heart as No. 2 Worry,” *New York Times*, March 25, 1987, sec. B4.

<sup>46</sup> Cole, ACT UP Oral History Project, 50.

<sup>47</sup> Bauer, ACT UP Oral History Project, 25.

<sup>48</sup> Ibid.

people, behind to deal with the fall-out.<sup>49</sup> Bauer also played an important role in teaching ACT UP members not be “police provocateurs” by crossing barricades or targeting the police.<sup>50</sup> With these important lessons, Bauer encouraged members to use civil disobedience as a means to project ACT UP’s message because, as they explained, “civil disobedience really does get you some attention.”<sup>51</sup> And, in order to force the government to respond to AIDS, ACT UP needed more attention.

During the spring and early summer of 1987, ACT UP gained considerable attention amongst the gay and lesbian communities of New York City and meetings grew from small and intimate to standing-room-only.<sup>52</sup> ACT UP piqued Maxine Wolfe, a Marxist-lesbian feminist with a history in civil rights and reproductive rights activism, when she saw its float at the Gay Pride Parade in June of 1987. Wolfe saw “mostly men” marching for the group and asked a member if ACT UP also had women participants. When he confirmed that it did, she decided to attend a meeting.<sup>53</sup> Wolfe felt struck by the hard reality that “people in that room were infected... had lover who had died... It was not an interesting political point. It was real.”<sup>54</sup> For Wolfe, this type of activism was different than the activism she did in the 1960s and 1970s. “There were no principles of unity that you had to adhere to... people didn’t go over [leaflets], as if they had to be

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<sup>49</sup> Ibid., p. 30.

<sup>50</sup> Ibid.

<sup>51</sup> Ibid., p. 27.

<sup>52</sup> Maxine Wolfe, transcript of an oral history conducted in 2004 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2004), <http://www.actuporalhistory.org/interviews/images/wolfe.pdf>, accessed December 06, 2017, 46.

<sup>53</sup> Ibid., p. 41.

<sup>54</sup> Ibid., p., 42.

politically correct...[and] you didn't have to read Marx" to participate in meetings.<sup>55</sup>

Wolfe had spent her entire adult life participating in, and most importantly feeling disappointed by, other movements, but ACT UP inspired her.

Maxine Wolfe long advocated for inclusion for women, people of color, and lesbians in political movements. She began working in the Civil Rights movement in the 1960s with the Brooklyn chapter of the Congress of Racial Equality and later marched on Washington behind Martin Luther King Jr. in 1963. However, during the late 1960s, Wolfe came out as a lesbian and began to further develop her Marxist-feminist ideology, causing her to move away from her Civil Rights activism and focus more on feminism.<sup>56</sup> She set out to earn her Ph.D. in psychology, and to explore other forms of activism. At one point, Wolfe joined a white Marxist-feminist consciousness-raising group, but she left shortly after the group rebuffed her attempts to discuss race more explicitly. "They were... white-skinned privileged people," she explained, who did not consider the lives of African American women in their conversations.<sup>57</sup> Too disappointed by the racial blindness of the group, Wolfe changed her focus to a growing reproductive rights group, the Committee for Abortion Rights and Against Sterilization Abuse (CARASA), in order to "argue for [her] Marxist politics in a feminist group, [rather] than feminist politics in a Marxist group."<sup>58</sup> She believed that CARASA would be the right fit.<sup>59</sup>

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<sup>55</sup> Ibid.

<sup>56</sup> Ibid.

<sup>57</sup> Ibid., p. 15.

<sup>58</sup> Ibid., p. 21.

<sup>59</sup> In *Undivided Rights: Women of Color Organizing for Reproductive Justice*, Loretta Ross, Elena Gutiérrez, Marlene Gerber, and Jael Silliman provide important context on CARASA. The women who founded CARASA in 1977 came from the anti-Vietnam War movement and civil rights movement and saw CARASA as a grassroots alternative to the

Maxine Wolfe had high expectations and wanted to work with other activists who understood the interwoven dynamics of race, class, gender, and sexuality—and CARASA ultimately fell short of that. She joined CARASA in 1979 but quickly felt that the group was more focused on networking with other groups than “organizing unorganized people.”<sup>60</sup> CARASA was “organizing with other groups and not really with women,” Wolfe recalled, so she sought to create a lesbian committee to better include lesbian politics into the organization and increase membership.<sup>61</sup> However, the majority of CARASA’s members were straight women who did not respond well to this initiative. “People starting freaking out,” Wolfe remembered. “As soon as we started mentioned lesbian stuff, it was like everything else we had done in the organization disappeared.”<sup>62</sup> During a meeting organized by Wolfe in which Andrea Dworkin argued that “men on the left [were] no different from men on the right,” many CARASA members got up and walked out. “Clearly,” Wolfe concluded, “homophobia was in that group.”<sup>63</sup> This homophobia made it “impossible” for Wolfe to stay with the group.

In addition to experiencing homophobia, Wolfe also left the group because of their reluctance to organize zap actions. With another member of the lesbian committee, Wolfe organized a protest in Washington D.C. in response to Kentucky representative Romano Mazzoli’s 1979 attempt to amend the Constitution to restrict women’s abortion access after legalization in 1973. For the action, women “broke up” the hearings by

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other national organizations, NARAL and Planned Parenthood. CARASA placed protection from sterilization abuse alongside the right to obtain an abortion in an effort to better reach a wider group of women, including women of color.

<sup>60</sup> Ibid., p. 17

<sup>61</sup> Ibid., p. 23.

<sup>62</sup> Ibid., p. 23.

<sup>63</sup> Ibid., p. 25.

disturbing the proceedings with chants and signs. The media responded by covering the action, resulting in “huge publicity” for CARASA.<sup>64</sup> This publicity “freaked” CARASA members who shunned the lesbians who had organized the zap action, and Wolfe and her lesbian allies in the group were “pushed out.”<sup>65</sup> Maxine Wolfe wanted to find action-oriented, racially inclusive, Marxist-lesbian organization to challenge racial and gender hierarchies, capitalism, and heterosexism; CARASA was not that group.

In search of the right activist community, Wolfe attended several meetings of various “lefty” causes in an attempt to find the right fit for her.<sup>66</sup> It was through her participation with the Gay and Lesbian Alliance Against Defamation that Wolfe learned of ACT UP and eventually found her fit. Despite the fact that the majority of ACT UP members were men, Wolfe still felt intrigued and interested in the group. “None of the lefty lesbians were there,” Wolfe recalled, but this did not sway her because of “the way [ACT UP] operated.” Members were free to express their ideas and received support from the group. And because ACT UP was founded on action, Wolfe got a sense that “if you had an idea, you could do it.”<sup>67</sup> Wolfe credited this sense to the fact that in ACT UP,

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<sup>64</sup> Ibid. Wolfe’s claim that a CARASA protest resulted in “huge publicity” remains unverified as CARASA did not appear in articles in the major national papers like *The New York Times* or *Washington Post*. However, coverage of CARASA clearly made its way to Dallas, Texas, as an editorial titled “Backward, March” in the May 5, 1981 *Dallas Morning News* included CARASA amongst other “old, umbrella leftist groups” that protested US involvement in El Salvador in 1981.

<sup>65</sup> Ibid., p. 28.

<sup>66</sup> Ibid., p. 31.

<sup>67</sup> Ibid., p. 42

“people were driven to do something.”<sup>68</sup> Wolfe felt excited that people in ACT UP had the passion and drive to create “real change.”<sup>69</sup>

Maxine Wolfe’s first action with ACT UP was a four-day long, twenty-four hour a day demonstration outside of Memorial Sloan Kettering Cancer Center on July 24, 1987, to protest their under-enrollment of people in their federally-funded AIDS clinical research trials.<sup>70</sup> Sloan Kettering was not “the worst, in terms of their AIDS services,” Wolfe explained, “but because... all this money had been allotted to research, and they enrolled practically nobody in these trials.”<sup>71</sup> Sloan Kettering received \$1.2 million for its designation as an AIDS clinical trial site, but had only thirty-four participants.<sup>72</sup> This under enrollment, argued Maria Maggenti to *New York Native* journalist Phil Zwickler, was “malicious neglect.”<sup>73</sup> The purpose of the demonstration was to expose this neglect and ask Sloan Kettering, and through the media, the general public, “why is this system not working? Why is the research not being done?” recalled Wolfe.<sup>74</sup> By joining in the organization of the protest, Wolfe made a name for herself and Sloan Kettering was the “first time I said anything political [in an ACT UP meeting], and then it just took off from

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<sup>68</sup> Ibid.

<sup>69</sup> Ibid., p. 43

<sup>70</sup> Phil Zwickler, “ACT UP Demonstrates at Sloan-Kettering,” *New York Native*, August 3, 1987, sec. 8. Claire Bond Potter studied the Sloan-Kettering protest in “Not in Conflict, But in Coalition: Imagining Lesbians at the Center of the Second Wave,” in *The Legacy of Second Wave Feminism in American Politics*. She argues that while ACT UP was mostly “white, bourgeois, and male,” the lesbians in ACT UP pushed the men to connect AIDS to issues that concerned them at the protest, like abortion rights, rape prevention, and the passage of the Equal Rights Amendment.

<sup>71</sup> Wolfe, ACT UP Oral History Project, 45.

<sup>72</sup> Phil Zwickler, “ACT UP Demonstrates at Sloan-Kettering,” *New York Native*, sec. 8.

<sup>73</sup> Ibid.

<sup>74</sup> Wolfe, ACT UP Oral History Project, 45.

there.”<sup>75</sup> Wolfe quickly became an outspoken member of ACT UP and many of the women in the group, particularly the younger lesbians, looked to her as a leader.

While there were several prominent straight female members of the organization, ACT UP/NY lacked lesbian leadership. “[Lesbians] spoke a lot,” Wolfe recalled, “but they weren’t leading committees.”<sup>76</sup> From her past experience with CARASA, Wolfe knew that lesbians needed to band together in order to enact any kind of real change and they were not doing so in ACT UP yet.<sup>77</sup> To rectify this and encourage more lesbian leadership in ACT UP, Wolfe organized “dyke dinners” in order to bring lesbians together to establish their unique purpose within the organization.<sup>78</sup> Dyke dinners provided women with an opportunity to meet without the presence of male members. Together, participants like Jamie Bauer, Maria Maggenti, filmmaker Jean Carlomusto, and Maxine Wolfe carved out a feminist space within the male-dominated group.<sup>79</sup>

Jean Carlomusto came to ACT UP with an established understanding that media and visibility was essential to raising public awareness of the AIDS crisis and challenging the government’s poor response. She was a graduate student at New York University in 1986 when Carlomusto learned about GMHC and its growing interest in creating

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<sup>75</sup> Ibid., p. 46. However, given Maxine Wolfe’s long history of political activism, it is unlikely that this was truly the first instance she became political in ACT UP.

<sup>76</sup> Ibid., p. 52.

<sup>77</sup> Ibid., p. 52.

<sup>78</sup> Ibid.

<sup>79</sup> Ibid. Maxine Wolfe followed in the tradition of other lesbian feminists, as Claire Bond Potter argues, whom forced heterosexual feminist organizers to deal with how factors of sexuality, but also race and class, created different needs for different women. Maxine Wolfe participated in a similar pattern in which she challenged the feminist organizations she participated in to better consider how activists could serve women of color.



educational videos about men's AIDS risks.<sup>80</sup> However, they needed someone with experience in audio-visual technology to keep producing films and hired Carlomusto to fill that role. There, she created *Living with AIDS* in order to “get information out there, get people connected with services.”<sup>81</sup> Different episodes of *Living with AIDS* focused on different aspects of AIDS; their first episode featured Carlomusto's friend Joey Lianti describing Kaposi's sarcoma and recommending makeup to cover up its trademark dark splotches. Another focused on available treatments and their potential side effects. In all, Carlomusto created 400 segments of *Living with AIDS* for GMHC from 1986 to 1994.

Through her work with GMHC in 1987, Jean Carlomusto had learned of ACT UP's first demonstration at Wall Street. She took her camera to film the event and felt swept up in excitement of the demonstration. “I surprised myself, because I just found myself at one point just using the camera as a weapon and pushing [police officers] out of the way to get to... the people in the street and to shoot this.”<sup>82</sup> Carlomusto caught the attention of ACT UP member Gregg Bordowitz, who was filming the protest for his piece *Testing the Limits*. Carlomusto joined Bordowitz and began to film ACT UP demonstrations across the city for the film. After they finished the project in June 1987, Carlomusto looked for a new project.

Jean Carlomusto and Gregg Bordowitz, along with ACT UP member and friend Catherine Saalfeld, created DIVA TV to film demonstrations and produce educational

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<sup>80</sup> Jean Carlomusto, transcript of an oral history conducted in 2002 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2004), <http://www.actuporalhistory.org/interviews/images/carlomusto.pdf>, accessed December 06, 2017, 4.

<sup>81</sup> Ibid., p. 6.

<sup>82</sup> Ibid., p. 11.

videos. DIVA TV's presence—and more specifically the presence of their cameras—usually kept police in line. “We were there to make sure that no one got roughed up, and also just to make sure that the police were following procedures,” Carlomusto recalled.<sup>83</sup> In this way, DIVA TV served a very practical purpose for the members of ACT UP.<sup>84</sup>

Catherine Saalfeld found her identity by channeling her activism through filmmaking. Because Saalfeld had joined the organization with her mother, she did not feel “out” like other more sexually adventurous members of ACT UP, despite being an open lesbian.<sup>85</sup> She also did not feel particularly comfortable with civil disobedience because it felt like a competition to see to “what distance you are going to go.”<sup>86</sup> With DIVA TV, however, Saalfeld found a space. She was a student in the Whitney Museum of American Art's Independent Study Program, a “one-year Marxist-indoctrination studio-art program,” and wanted to combine her love of filmmaking, art criticism, and activism. Beginning in 1967, the Whitney Museum offered rigorous and highly competitive programs to students of art history and studio art. Students, according to Saalfeld, had extensive readings in theory and psychoanalysis and Marxism and cultural psych, anthropology, [and] film studies.”<sup>87</sup> Through the Whitney program, Saalfeld met

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<sup>83</sup> Ibid., p. 12.

<sup>84</sup> Alexandra Juhasz details the origins of DIVA TV and other uses of film in AIDS activism in her article “So Many Alternatives: The Alternative AIDS Video Movement.” *Cineaste* 20 (1994): 32-35. I examine this article further in Chapter Five.

<sup>85</sup> Catherine (Saalfeld) Gund, transcript of an oral history conducted in 2007 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2007), <http://www.actuporalhistory.org/interviews/images/gund.pdf>, accessed December 06, 2017, 15.

<sup>86</sup> Ibid., p. 21.

<sup>87</sup> Ibid., p. 25.

Gregg Bordowitz and other future members of DIVA TV, Ellen Spiro and Ray Navarro.<sup>88</sup> Together with Spiro and Navarro, Saalfeld first attended ACT UP meetings.

Saalfeld argued that there was a direct relationship between her readings at the Whitney Program and the creation of DIVA TV.<sup>89</sup> DIVA TV allowed Saalfeld to “really make media that undermined media, and that talked about media and unpacked media, and using the media to tell on the media.”<sup>90</sup> She believed that by using the camera as a tool, activists could publicize the messages of people living with AIDS. DIVA TV provided people with “a chance to speak for themselves.”<sup>91</sup> In 1991, she argued that daily papers wanted to minimize the activism of ACT UP in order to serve their own corporate interests.<sup>92</sup> DIVA TV protested through the use of their camera in order to ensure that authentic images of people with AIDS and the AIDS movement would be more difficult to erase.<sup>93</sup>

To depict accurate representations of AIDS and AIDS activism, the members of the DIVA TV collective recognized that people with AIDS “took the lead in mobilizing the political will and energies necessary to deal with the AIDS crisis.” Thus, DIVA TV’s “essential goal [was] inclusivity,” and members accomplished this by showcasing those people who “[had] never been put out there or that you haven’t seen.”<sup>94</sup> The DIVA TV collective used video as their mode of activism and highlighted the contributions of less

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<sup>88</sup> Ibid., p. 27.

<sup>89</sup> Ibid., p. 29.

<sup>90</sup> Ibid., p. 28.

<sup>91</sup> Ibid., p. 30.

<sup>92</sup> Catherine Saalfeld and Ray Navarro, “Shocking Pink Praxis: Race and Gender on the ACT UP Frontlines,” in *Inside/Out: Lesbian Theories, Gay Theories*, Ed. Diana Fuss (New York: Routledge, 1991), 345.

<sup>93</sup> Ibid., 346.

<sup>94</sup> Catherine Gund, ACT UP Oral History Project, p. 30.

visible people with AIDS, like the women in ACT UP. Carlomusto and Saalfeld's videos, particularly the one that showcased an arrest in which many of the women were illegally strip searched by the police, passed from hand-to-hand in ACT UP and encouraged others, like Alexandra Juhasz, to take up the medium.

Alexandra Juhasz set out to make a film about woman and AIDS. She was a young feminist and also a student at the Whitney Museum program when she decided to make a film and turned to Jean Carlomusto for help.<sup>95</sup> Juhasz wanted to "make a piece of women and AIDS because I was a feminist and I thought about things through women's experience."<sup>96</sup> Carlomusto featured the piece, titled *Women and AIDS*, on her GMHC project *Living with AIDS* in 1986.<sup>97</sup> In the piece, Juhasz argued that racism, sexism, and homophobia all conflated to prevent women with AIDS from receiving adequate AIDS education. The mainstream media, like *Time* and *Newsweek* magazines, "were saying that women didn't need to worry. They were saying that it wasn't a woman's issue."<sup>98</sup> The purpose of *Women and AIDS*, then, was to teach women of their AIDS risks. Juhasz recalled, "I thought, women need to be told to have safe sex. This is crazy. You're going to kill people."<sup>99</sup> Juhasz channeled her own long history of feminist activism into fighting the AIDS crisis in women.

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<sup>95</sup> Alexandra Juhasz, transcript of an oral history conducted in 2003 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2003), <http://www.actuporalhistory.org/interviews/images/juhasz.pdf>, accessed December 06, 2017, 12.

<sup>96</sup> Ibid.

<sup>97</sup> Ibid., p. 14.

<sup>98</sup> Ibid.

<sup>99</sup> Ibid., p. 16.

Even as a high school student, Alexandra Juhasz was interested in feminism and activism and when she went to Amherst College in 1982, she further developed this passion.<sup>100</sup> While Amherst, according to Juhasz was a “really uptight, conservative, elitist institution,” she banded together with other “progressive” students to study feminist and gender studies.<sup>101</sup> With this group and with the encouragement of University of Massachusetts professor Jan Raymond, Juhasz worked in creating sexual harassment policies for Amherst and formed peer education programs centered on rape prevention.<sup>102</sup> When she graduated Amherst and was accepted into the Whitney Museum independent study program, Juhasz moved to New York City. While working with Jean Carlomusto and GMHC, Juhasz learned about ACT UP through one of their early demonstrations.<sup>103</sup>

Juhasz “chanced” upon an ACT UP rally in the summer of 1987 and liked how the members talked about social issues.<sup>104</sup> She knew she stumbled across something important when she heard members “talking about America... identity... talking about what’s wrong—exactly in the way that I wanted to speak.”<sup>105</sup> Juhasz had struggled to find a place for her activism in New York City, so when she saw members of ACT UP talking about the AIDS crisis, she felt like she had finally found a home. “As a feminist, coming into AIDS activism, this was exactly the issue around which everything I was already concerned with crystallized,” Juhasz explained.<sup>106</sup> When she began to regularly attend ACT UP meetings, Juhasz heard from other members “who would bring up history, who

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<sup>100</sup> Ibid., p. 2.

<sup>101</sup> Ibid., p. 2.

<sup>102</sup> Ibid., p. 3.

<sup>103</sup> Ibid., p. 5.

<sup>104</sup> Ibid.

<sup>105</sup> Ibid.

<sup>106</sup> Ibid., p. 6.

would bring up tactics, who would bring up other struggles.”<sup>107</sup> She felt in “awe” of their knowledge and histories and turned towards the women in ACT UP, whom she considered experienced “politicos,” to learn more.<sup>108</sup>

While Alexandra Juhasz certainly learned from the other women in ACT UP, she also quickly became a leading figure in the group. Within only a few months of attending her first meeting in the summer of 1987, Juhasz teamed up with Maxine Wolfe to create a women’s committee.<sup>109</sup> The group formed rather informally—the first members of the women’s committee, later renamed Women’s Caucus, were the women who sat with Juhasz and Wolfe at meetings.<sup>110</sup> Many of these women were also regular attendees of Maxine Wolfe’s “dyke dinners” which brought some tension to the group, as Juhasz was not a lesbian.<sup>111</sup> She recalled Maxine Wolfe and Maria Maggenti both “were really pissed at me when they found out I was straight.”<sup>112</sup> Despite this, the women’s committee evolved into a more formal Women’s Caucus by the fall of 1987. As shown by Jennifer Brier, the Women’s Caucus members believed that the best way to fight AIDS was to connect prevention with treatment, rather than focusing solely on treatment options, like the Treatment and Data Committee (T&D).<sup>113</sup> The members, like Juhasz, Wolfe, Maggenti, Jean Carlomusto, Rebecca Cole, and civil rights and reproductive rights activist Marion Banzhaf met regularly at a local diner as an escape from the male-

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<sup>107</sup> Ibid., p. 7.

<sup>108</sup> Ibid., p. 6.

<sup>109</sup> Ibid., p. 17.

<sup>110</sup> Ibid., p. 17.

<sup>111</sup> Ibid., p. 7.

<sup>112</sup> Ibid., p. 8.

<sup>113</sup> Brier, *Infectious Ideas*, 162.

dominated ACT UP.<sup>114</sup> They argued that ACT UP had to tackle the racism and sexism that prevented women with AIDS from education and treatment.<sup>115</sup>

Marion Banzhaf, who joined ACT UP as an experienced activist in the women's health movement, believed that sexism from men in the group prevented women's ideas from being heard. To address this, she argued that women needed to form a committee that would have representation on the Steering Committee in order to "influence the direction of ACT UP a little more."<sup>116</sup> Banzhaf wanted the male members of ACT UP to pay closer attention to the lessons learned in the women's health movement. She argued that, "The women's health movement sort of paved the way for AIDS activism in terms of challenging the control of doctors in the first place, and starting to democratize health care."<sup>117</sup> Banzhaf, who had worked at a feminist health collective in Florida before moving to New York City, hoped to direct ACT UP to better advocate for women, rather than relegating them to the side of larger demonstrations.<sup>118</sup>

Marion Banzhaf had a long history as an activist, particularly in women's health activism. After graduation, she applied for a job at the Florida Women's Health Collective and began her work as a health educator. After unintentionally becoming pregnant as a college student at the University of Florida, Banzhaf used the Clergy Consultation Referral Services, a collective of Catholic clergy who helped women find

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<sup>114</sup> Wolfe, ACT UP Oral History Project, 52.

<sup>115</sup> Brier, *Infectious Ideas*, 162.

<sup>116</sup> Marion Banzhaf, transcript of an oral history conducted in 2003 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2007), <http://www.actuporalhistory.org/interviews/images/banzhaf.pdf>, accessed December 06, 2017, 51.

<sup>117</sup> *Ibid.*, p. 50.

<sup>118</sup> *Ibid.*

abortion providers before legalization, to get an abortion in New York City.<sup>119</sup> This experience led her to seek out a job at the Feminist Women's Health Center where Risa Denenberg worked. Banzhaf worked as a health care worker and educator, both providing women with health services, including abortion, and a feminist education.<sup>120</sup> With her job at the health center, Banzhaf traveled around the country teaching women how to perform their own gynecological care, including menstrual extractions. Unapologetically pro-abortion and thus decidedly politically "left of the women's health movement," according to Banzhaf, her activism took her to the more progressive New York City in 1983.<sup>121</sup>

Her activism evolved when Banzhaf moved to New York City and she worked as a typesetter for the Black Panther Party. When her friend and fellow Panther Kuwasi Balagoon died from complications from AIDS, Banzhaf became interested in AIDS activism. In New York, Banzhaf expanded her activism to include "various black organizations," the lesbian and gay movement, and through that, AIDS activism.<sup>122</sup> After Balagoon's death, Banzhaf began attending ACT UP meetings after seeing other women participate in the meetings at the Gay and Lesbian Community Center.<sup>123</sup> Banzhaf was worried that the increasing discrimination against gay men with HIV/AIDS would soon

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<sup>119</sup>Ibid., p. 13.

<sup>120</sup> Ibid., p. 26.

<sup>121</sup> Ibid., p. 19, 21. Loretta Ross writes in her chapter "African American Women and Abortion" in Rickie Solinger's *Abortion Wars: A Half Century of Struggle, 1950-2000* p. 178 that the Clergy Consultation Service, founded in 1967, referred women in need of an abortion to abortion providers before legalization. Ross estimates that the group helped thousands of women obtain safe abortions. Both Ross and Jennifer Nelson in *More Than Medicine: A History of the Feminist Women's Health Movement* p. 62 point that the Clergy Consultation Service often operated outside of U.S. borders to connect women with abortion practitioners.

<sup>122</sup> Ibid., 39.

<sup>123</sup> Ibid., 42.



“bleed over to the lesbian community.”<sup>124</sup> Thus, she joined the “phenomenon” that was ACT UP and began to look for ways to integrate her lesbian feminism into the group.

The women in ACT UP first tackled the issue of poor media representation of women’s risks of AIDS. When Rebecca Cole brought the December 1987 issue of *Cosmopolitan* to one of Wolfe’s “dyke dinners,” the participants were outraged to discover an article suggesting that women had no reason to worry about HIV/AIDS. They brought the issue to the next Women’s Caucus meeting and passed the article around.<sup>125</sup> The article’s author, Dr. Robert Gould, a psychologist with no experience in HIV/AIDS, argued that warnings about AIDS in the heterosexual community were overblown and unfounded.<sup>126</sup> Dr. Gould lamented that just when women began to feel sexually free after the work of women in the 1960s and 1970s, they were “cautioned to hold onto chastity for dear life or face the deadly risk of contacting AIDS, the fatal disease.”<sup>127</sup> According to the article, heterosexual women who practiced “ordinary” sex, defined by Gould as

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<sup>124</sup> Ibid., 50

<sup>125</sup> Carlomusto, ACT UP Oral History Project, 16.

<sup>126</sup> Robert E. Gould, M.D., “Reassuring News About AIDS: A Doctor Tells Why You May Not Be At Risk,” *Cosmopolitan*, December 1987, 146. Paula Treichler too examines the articles and argues in “AIDS, Gender, and Biomedical Discourse: Current Contests for Meaning,” in *AIDS: The Burdens of History*, ed. Elizabeth Fee and Daniel M. Fox (Berkeley, 1988), 190-267 that despite historical associations of disease and women’s bodies, women have been excluded from the AIDS narrative, scientific literature, and even women’s own conceptions of HIV/AIDS. Treichler points to the medical community’s obsession with homosexuality stemming from recent battles with Hepatitis B. Despite the discovery of the virus, which perhaps could have stopped the association between homosexuality and HIV, Treichler argues that women and feminists have failed to sever the connection. Disappointingly, media, including women’s magazines, encouraged women to traditional monogamous relationships and relied on a “risk group” analysis that served to “other” non-white, upper middle class women, leaving room for much-needed feminist analysis of HIV/AIDS and the messages of safe sex.

<sup>127</sup> Ibid.

penile penetration in a well-lubricated vagina, had no risk of contracting the disease.<sup>128</sup>

Dr. Gould's analysis centered the use of "risk groups," which activists argued was a flawed understanding of assessing one's risk to AIDS.<sup>129</sup> Sociologist and activist Cindy Patton explained that "risk groups" broke women into categories based on what doctors believed led to their HIV exposure. This reflected the belief of medical researchers and politicians that some women "deserved" the disease because of their risky behavior, while others with HIV were more sympathetic because they had innocently been exposed to the virus through generous "womanly" behavior like, for instance, a blood transfusion. Basing his argument on this faulty "risk group" methodology, Gould argued, people who practiced abnormal sex, such as anal sex or rough sex characterized by "macho thrusting," did have reason to worry.<sup>130</sup> Instead, Gould claimed, most heterosexual women should reject the "mounting fear and false alarm" of AIDS.<sup>131</sup> While he admitted that AIDS caused "pain and torment" for those who lost loved ones to the disease, the fear of AIDS spreading to the heterosexual community was "killing our sexual lives" which, argued Gould, "may prove more destructive in the long run than the AIDS virus

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<sup>128</sup> Ibid.

<sup>129</sup> This systematic categorization of women with AIDS, sociologist Cindy Patton explained, pitted women against each other in risk groups which made it difficult to organize and create alliances, and kept power and knowledge in the hands of male politicians, and away from women who did not conform to gender expectations. In turn, medical research categorized women with AIDS as either the "cause of infection" or as "those who needed to be protected," either a "passive vessel or a moral pariah." Cindy Patton, *Last Served?: Gendering the HIV Pandemic*, Social Aspects of AIDS (Bristol, PA: Taylor & Francis, 1994).

<sup>130</sup> Ibid.

<sup>131</sup> Ibid., 204.

itself.” Jean Carlomusto recalled feeling “absolutely appalled” that Dr. Gould would make such outrageous claims.<sup>132</sup>

Dr. Gould was not alone in his faulty understanding of AIDS. While women had HIV as early as 1983, popular media across the board downplayed women’s risks because of the association between AIDS and deviant sex. In 1988, Paula Treichler pointed to the April 1986 issue of *New Woman*, amongst others, in which writer Erica Jong cited a 1985 issue of *Discover* that told women that AIDS was “a difficult disease to catch” for women, since it was “borne of blood and semen.”<sup>133</sup> AIDS, she continued, was a consequence of anal intercourse or having sex with drug users.<sup>134</sup> The message here, as Treichler explained, was the “normal” women were not exposed to AIDS. Magazine articles across the country contained these messages that both “trivialized” the gravity of the AIDS crisis while simultaneously encouraging readers to return to “normal” sex to save themselves from the disease.<sup>135</sup> In the rare instances where these articles did acknowledge the rates of heterosexual transmission in Africa, journalists explained away women’s risk with racist stereotypes about “African culture.”<sup>136</sup>

Dr. Gould’s article was no exception. Women in ACT UP were shocked by the overt racism in the piece.<sup>137</sup> In the article, Dr. Gould continued to claim that the reason for high rates of heterosexually transmitted AIDS in Africa was due to “cultural

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<sup>132</sup> Carlomusto, ACT UP Oral History Project, 18.

<sup>133</sup> Paula Treichler, “AIDS, Gender, and Biomedical Discourse: Current Contests for Meaning,” in *AIDS: The Burdens of History* (Berkeley: University Of California, 1988), 223.

<sup>134</sup> Ibid., p. 224.

<sup>135</sup> Ibid., p. 227.

<sup>136</sup> Ibid., p. 224.

<sup>137</sup> Ibid.

differences.”<sup>138</sup> The first of these cultural differences, according to Dr. Gould, was that Africans were unlikely to discuss homosexuality within their communities. Therefore, the high rates of AIDS in Africa, argued Gould, were probably due to homosexual sex. This “reluctance” to discuss homosexuality, then, made Dr. Gould “question the information reported by African researchers.”<sup>139</sup> And even if their numbers were correct, he wrote that “many men in Africa take their women in a brutal way, so that some heterosexual activity regarded as normal by them would be closer to rape by our standards and therefore be likely to cause vaginal lacerations.”<sup>140</sup> The women in ACT UP believed that these claims in the article were equally as ridiculous as they were racist and dangerous.<sup>141</sup>

Based on faulty science and a problematic way of understanding the transmission of AIDS, the “dyke dinner” attendees wanted Dr. Gould to retract his article. Rebecca Cole, Maria Maggenti, Maxine Wolfe, and Jean Carlomusto planned a video sting in which they would go to Dr. Gould’s office to confront him and force a retraction. They brought with them Denise Ribble, a nurse who worked at the Community Center clinic and was thus very familiar with HIV/AIDS.<sup>142</sup> Cole recalled that Dr. Gould was completely open to them. “He let us bring a camera! It was so great!”<sup>143</sup> Under the guise of creating a documentary, the Women’s Caucus members drilled Dr. Gould for the sources of his misinformation. When he shrugged them off by claiming he had read it somewhere, Maria Maggenti confronted the psychiatrist with their true purpose. She

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<sup>138</sup> Robert E. Gould, M.D., “Reassuring News About AIDS: A Doctor Tells Why You May Not Be At Risk,” *Cosmopolitan*, December 1987, 147.

<sup>139</sup> Ibid.

<sup>140</sup> Ibid.

<sup>141</sup> Carlomusto, ACT UP Oral History Project, 17.

<sup>142</sup> Cole, ACT UP Oral History Project, 52.

<sup>143</sup> Ibid.

asked, “How could you read that something that is not even corroborated scientifically and then put it in a magazine that millions of women read?”<sup>144</sup> Maxine Wolfe, meanwhile, questioned Dr. Gould’s racist analysis that African men engage in more brutal sex practices than American men.<sup>145</sup> Despite their efforts, Dr. Gould refused to write a retraction.

The Women’s Caucus planned their first demonstration in response to Dr. Gould’s *Cosmo* article when both he and editor Helen Gurley Brown refused to retract the article.<sup>146</sup> Dr. Gould was a friend of Brown’s and refused to meet with the activists again.<sup>147</sup> So, the Women’s Caucus held a demonstration outside of the Hearst Corporation’s building on West 57th Street in January of 1988. This was ACT UP’s first demonstration that was organized by women like Maxine Wolfe and Jamie Bauer who had considerable experience in civil disobedience.<sup>148</sup> Three hundred demonstrators formed a picket outside the offices, chanting and distributing leaflets to passersby that explained why ACT UP turned their ire to *Cosmo*.<sup>149</sup> The leaflet, titled “Don’t Go to Bed With Cosmo,” explained that AIDS was the leading cause of death for young women in New York City and that the CDC’s own statistics claimed that twenty-six percent of

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<sup>144</sup> Maggenti, ACT UP Oral History Project, 27.

<sup>145</sup> Ibid. 27

<sup>146</sup> Wolfe, ACT UP Oral History Project, 58.

<sup>147</sup> Committees, Women's Action Committee (3 of 7), 1987-1989. 1987-1989. MS ACT UP: The AIDS Coalition to Unleash Power: Series VII. Committees Box 73, Folder 3. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nSYe0>. Accessed 25 Sept. 2018.

<sup>148</sup> Wolfe, ACT UP Oral History Project, 58.

<sup>149</sup> Ibid.

women diagnosed with the disease contracted it through heterosexual sex.<sup>150</sup> The leaflet continued, “Heterosexual, lesbian and bisexual women need accurate information so that they can enjoy all forms of sexual activity AND LIVE TO TELL THE NEXT GENERATION OF WOMEN HOW TO DO IT.”<sup>151</sup> The Women’s Caucus was not anti-sex, but rather anti-AIDS and thus urged the magazine to correct its article and advertisers to pull their ads from the magazine.<sup>152</sup> Unlike previous ACT UP demonstrations, the Women’s Caucus did not alert the police about the demonstration ahead of time or negotiate with them because “everything we did was within our constitutional rights and legal,” Wolfe wrote later in 1989.<sup>153</sup> Despite this, two demonstrators were arrested.<sup>154</sup>

The demonstration resulted in considerable media attention and prompted responses from scientists across the country.<sup>155</sup> Even Surgeon General C. Everett Koop weighed in, saying that the *Cosmo* article had “split the scientific community” but that health officials had to remain staunch in their commitment to teaching about AIDS risks to heterosexuals.<sup>156</sup> Meanwhile, in an article in the *American Journal of Medicine*,

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<sup>150</sup> Committees, Women's Caucus, January, 1988-March, 1989. January, 1988-March, 1989. MS ACT UP: The AIDS Coalition to Unleash Power: Series VII. Committees Box 73, Folder 12. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nSiJ9>. Accessed 4 Feb. 2018.

<sup>151</sup> Ibid.

<sup>152</sup> Ibid.

<sup>153</sup> Ibid.

<sup>154</sup> Ibid.

<sup>155</sup> Committees, Women's Action Committee (3 of 7), 1987-1989. 1987-1989. MS ACT UP: The AIDS Coalition to Unleash Power: Series VII. Committees Box 73, Folder 3. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nSYe0>. Accessed 25 Sept. 2018.

<sup>156</sup> Joe Nicholson, “Koop Kicks About ‘Safe-Sex’ Press,” *New York Post*, February 20, 1988, sec. 7.

Rebecca Cole explained that Dr. Gould's article demonstrated a serious "misunderstanding of women's anatomy and psychology."<sup>157</sup> Many women, explained Cole, had tears in their vaginal walls even if their vaginas were healthy and should use condoms during sex. Furthermore, she argued, Dr. Gould's article told women, "Don't bother your man with that flimsy little thing that could save your life."<sup>158</sup> This article, then, presented the Women's Caucus and other AIDS educators with a dilemma as millions of young women read in *Cosmo* that they did not have to worry about condoms and AIDS.

The filmmakers in the Women's Caucus, Maria Maggenti and Jean Carlomusto, also worked to correct *Cosmo*'s misinformation and created the piece *Doctors, Liars, and Women* (1988) to highlight ACT UP's response and provide safer sex information. The piece showed the interview between activists and Dr. Gould, as well as the demonstration outside of the Hearst building and interviews with the members of the Women's Caucus. In her interview, Maxine Wolfe described that the confrontation with Dr. Gould allowed the women in the room to "coalesce because we all felt the power" of presenting the psychiatrist with more recent medical information and revealing his ignorance of AIDS in women.<sup>159</sup> Jamie Bauer, who participated in the demonstration, agreed with Wolfe's analysis. For her, the *Cosmo* action provided activists with a clear enemy in Dr. Gould

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<sup>157</sup> Published and near Print Material, Media, January-February, 1988. January-February, 1988. MS ACT UP: The AIDS Coalition to Unleash Power: Series X. Published and near Print Material Box 134, Folder 19. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tMZ28>. Accessed 4 Feb. 2018.

<sup>158</sup> Ibid.

<sup>159</sup> Jean Carlomusto and Maria Maggenti, *Doctors, Liars, and Women*, Video, 1988, <https://vimeo.com/55793020>. Accessed January 11, 2018.

and the magazine.<sup>160</sup> Likewise, Maria Maggenti explained that *Cosmo* solidified the Women's Caucus as a home for lesbian and straight women in ACT UP.<sup>161</sup> *Doctors, Liars, and Women* demonstrated this solidarity only a few days later when the Women's Caucus took over the television show *People Are Talking*.

Together, members of the Women's Caucus attended a screening of *People Are Talking* when they learned that it would feature an entirely male panel on AIDS.<sup>162</sup> The panel even included Dr. Gould. Activists Rebecca Cole, Maria Maggenti, and Jean Carlomusto sat in the audience and directed questions to the panel about women's risks and corrected the panel-members when they offered incorrect information. When the host accused the activists of hampering dialogue and the "exchange of ideas," ACT UP ally and author of the guide "Advice for Life: A Woman's Guide to AIDS," Chris Norwood, took the stage.<sup>163</sup> When the show producers kicked out Norwood, along with the members of the Women's Caucus, Maria Maggenti argued in *Doctors, Liars, and Women*, producers made women invisible.<sup>164</sup> "The only thing that was left," she explained, "was a debate about epidemiological truth and whether or not so-and-so was a doctor and whether there was proof of heterosexual transmission irrespective of the fact that women have AIDS."<sup>165</sup> Jean Carlomusto affirmed Maggenti's analysis and later argued that *People Were Talking* was "the first time" that women's activism "subvert[ed]

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<sup>160</sup> Ibid.

<sup>161</sup> Ibid.

<sup>162</sup> Carlomusto, ACT UP Oral History Project, 18.

<sup>163</sup> Ibid.

<sup>164</sup> Ibid.

<sup>165</sup> Ibid.



the dominant media messages” which would become a staple of ACT UP’s activism.<sup>166</sup>

As Carlomusto and Maggenti played *Doctors, Liars, and Women* at gay and lesbian events across the city, they corrected information but also advertised ACT UP, and most importantly, that women were key members of the organization.<sup>167</sup>

The *Cosmo* action proved to both the women and men in ACT UP that women belonged in the organization. “As a group, we brought something to ACT UP by the women organizing together,” explained Wolfe in *Doctors, Liars, and Women*.<sup>168</sup> Maria Maggenti agreed and told viewers that it was “particular significant that women are as involved as they are, that they know the issues, and that they’re willing to take anyone on.”<sup>169</sup> Through *Cosmo*, the Women’s Caucus brought significant attention to ACT UP and wanted to capitalize on that advantage by further directing the group to focus on women’s issues. Jean Carlomusto hoped that “more women in the group will feel comfortable taking the camera... and documenting their own lives. Women have been saying for years now what’s personal is political and our personal lives are a microcosm of what’s going on in the entire political scene.”<sup>170</sup> ACT UP, then, provided women with a platform to tell their own stories while taking on the long-standing issues that prevented women from accessing accurate AIDS information.

One of these long-standing issues was the socially accepted belief that women were responsible for practicing safer sex by negotiating condom use with disinterested or disinclined male sexual partners. As a part of ACT UP’s Nine Days of AIDS

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<sup>166</sup> Ibid., p. 19.

<sup>167</sup> Carlomusto and Maggenti, *Doctors, Liars, and Women*.

<sup>168</sup> Ibid.

<sup>169</sup> Ibid.

<sup>170</sup> Ibid.

Demonstrations, the Women's Caucus took on the cause of sex-positive safer sex education for young women.<sup>171</sup> On the morning of May 4<sup>th</sup>, activists set up tables outside of nine high schools in each of the five boroughs of New York City to pass out erotic safer sex information. Members wanted to educate young women on the use of condoms and dental dams, while also demonstrating that the use of prophylaxis did not have to take away from the sensuality of sex. As Maxine Wolfe put it, "Younger women are not getting the safer sex educational materials they need" and that the Women's Caucus should meet that need.<sup>172</sup> By encouraging barrier methods and condom negotiation, the Women's Caucus hoped to protect young women. But the goal of the campaign was not merely to distribute information on barrier methods, such as condoms and dental dams, but also on how to "negotiate safer sex in situations where [young women] may not feel they have the power to ask for what they want."<sup>173</sup> The Women's Caucus believed that they were empowering women to advocate for their safety and sexuality.

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<sup>171</sup> Actions / Demonstrations / Zaps, National Spring AIDS Action, NY. April 29-May 7, 1988. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 13, Folder 14. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nTLy3>. Accessed 25 June 2018. In *Intimate Matters* p. 355-357, John D'Emilio and Estelle B. Freedman explain that while the Reagan administration responded sluggishly to the AIDS crisis, AIDS organizations published and publicized guidelines for "safe-sex" that encouraged condom use in order to slow the spread of HIV/AIDS. However, these guidelines also encouraged a return to monogamy, and activists argued, shamed people for having natural sexual appetites. Instead of encouraging people to return to "dating, romance, and monogamous relationships," sex-positive safe sex advocates argued that pleasurable and fun sex could also be safe sex.

<sup>172</sup> Maxine Wolfe, "How to Use This Handbook to Translate Issues into Action," in *The ACT UP Women's Caucus Women and AIDS Handbook*, ed. Maria Maggneti (New York, NY: ACT UP, 1990), sec. 5.

<sup>173</sup> Ibid.

The Caucus also wanted to target men. That evening, the Caucus organized a demonstration at Shea Stadium during a Mets game to encourage condom use for straight men. Maxine Wolfe and Rebecca Cole chose Shea Stadium because, according to Carlomusto, it was a “male space [that they turned] into a medium for a message,” by targeting men to take responsibility for condom use.<sup>174</sup> Advertised in the *Village Voice*, the demonstration at Shea targeted “the bastion of male heterosexuality.”<sup>175</sup> The Caucus members wanted to “raise consciousness about heterosexual men’s responsibility for safer sex” by leafleting and distributing condoms.<sup>176</sup> Jean Carlomusto argued that conversations about safe sex usually placed women in the position of being solely responsible for their health. Even in the Women’s Caucus, she argued, the members’ “feminist backgrounds,” along with their “strategies... borrowed from the women’s movement,” led them to believe that they needed to put the “onus” of acting on safer sex information “always on women.”<sup>177</sup> At the Shea Stadium demonstration, then, the Caucus sought to counter this general burden on women by placing sexual responsibility on men, encouraging condom use in order to protect women from AIDS. “Our goal,” according to

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<sup>174</sup> Ibid., p. 24.

<sup>175</sup> David France, “ACT UP Fires Up,” *Village Voice*, May 3, 1988, p. 36 in Published and near Print Material, Media, May-June, 1988. May-June, 1988. MS ACT UP: The AIDS Coalition to Unleash Power: Series X. Published and near Print Material Box 134, Folder 21. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/6AQPZ9>. Accessed 20 Mar. 2018.

<sup>176</sup> Actions / Demonstrations / Zaps, National Spring AIDS Action, NY. April 29-May 7, 1988. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 13, Folder 14. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tMcH5>. Accessed 23 June 2018.

<sup>177</sup> Jean Carlomusto, ACT UP Oral History Project, 25.

Wolfe, was to “raise consciousness, educate, and HAVE A GOOD TIME!”<sup>178</sup> In addition to handing out information and condoms, ACT UP also “unfurl[ed] large banners” that contained ACT UP slogans like “SILENCE=DEATH,” “AIDS KILLS WOMEN,” and “NO GLOVE, NO LOVE.”<sup>179</sup> The Shea Stadium demonstration focused entirely on women’s safety and male responsibility to prevent the disease. Leaflets in both English and Spanish urged men to “not endanger the women [they] love” and to use condoms to protect women.<sup>180</sup>

The demonstration at Shea Stadium encouraged new members to dedicate themselves further to the organization. The demonstration proved to be an excellent recruiting tool for new member Polly Thistlethwaite because of the rush of leaving her comfort zone. Thistlethwaite explained that at the demonstration “there was no hostility. People were raising their glasses to us in this section. I felt like it was, despite its risk, leaving the gay ghetto, leaving the Village and going to Shea fucking Stadium, it was really successful. It was a lot of fun and very effective demonstration.”<sup>181</sup> However, not all game attendees found the protest as fun and effective as ACT UP’s members. At least one baseball fan complained to *Newsweek Magazine*, saying that “AIDS is a fearful topic.

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<sup>178</sup> Ibid.

<sup>179</sup> Ibid.

<sup>180</sup> Actions / Demonstrations / Zaps, National Spring AIDS Action, NY. April 29-May 7, 1988. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 13, Folder 14. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tMcH5>. Accessed 23 June 2018.

<sup>181</sup> Polly Thistlethwaite, transcript of an oral history conducted in 2013 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2013), <http://www.actuporalhistory.org/interviews/images/thistlethwaite.pdf>, accessed June 26, 2017, 14.

This is totally inappropriate.”<sup>182</sup> Despite this, ACT UP members like Thistlethwaite believed they were welcomed warmly to the stadium. Thistlethwaite, a lesbian raised by an “anti-war liberal Democrat, pro-feminist, pro-integration” father, was not new to social activism.<sup>183</sup> Even as a teenager in Decatur, Illinois, Thistlethwaite participated in a teachers’ strike led by her father.<sup>184</sup> After earning her master’s degree in library sciences from the University of Illinois Urbana-Champaign, Thistlethwaite jumped around from Chicago to New Haven for work, eventually landing New York City.<sup>185</sup> Settling in New York, Thistlethwaite “immediately” began working with the Lesbian Herstory Archives, created in the 1970s in order to preserve lesbian history.<sup>186</sup> It was at the archives that Thistlethwaite met Maxine Wolfe, who had invited her to the Shea Stadium demonstration.

Polly Thistlethwaite connected with the Shea Stadium action’s message. “All of the advertising for condoms had been, like, women should buy condoms and women should be the ones responsible for managing the condom,” Thistlethwaite explained.<sup>187</sup> Shea Stadium, however, represented a “shift of focus.”<sup>188</sup> However, encouraging men to use condoms was not the only shift in ACT UP’s focus as seen through their presence at Shea Stadium. As *New York Times* journalist Thomas Morgan explained, “the Shea demonstration took [ACT UP’s] controversial message out of Manhattan to working-

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<sup>182</sup> Eloise Salholz and Peter McKillop, “Acting Up to Fight AIDS: A Group’s Angry Tactics,” *Newsweek Magazine*, June 6, 1988, p. 42.

<sup>183</sup> *Ibid.*, p. 1-2.

<sup>184</sup> *Ibid.*, p. 2.

<sup>185</sup> *Ibid.*, p. 5.

<sup>186</sup> *Ibid.*, p. 14.

<sup>187</sup> *Ibid.*, p. 15.

<sup>188</sup> *Ibid.*

class Queens, marking the group's growing sophistication and its movement toward more mainstream forms of protest."<sup>189</sup> Morgan explained further that ACT UP was unique in its broad spectrum of members, characterized as "predominantly young, angry, and well-educated men and women between the ages of 25 and 34."<sup>190</sup> While ACT UP flipped the message about safer sex and condoms, it also grew in notoriety through media coverage and word of mouth as a result of the Shea demonstration.<sup>191</sup>

This first stage of women's activism within ACT UP represented a coalescence of women who were generally career activists, firmly feminist, and most of whom were white lesbians. In this first year, women tackled the goal of safer sex for women to protect them from AIDS. To do this, they formed an informal caucus to correct poor media representations of women with AIDS and women's risks of AIDS and encourage wider spread condom use. Many Women's Caucus members, like Rebecca Cole, Maxine Wolfe, Jamie Bauer, and Marion Banzhaf had previous experience with civil disobedience and zap action through their reproductive rights, civil rights, and anti-war activism. Others, like Maria Maggenti, Jean Carlomusto, Catherine Saalfield, and Alexandra Juhasz, had some experience with activism, but were generally drawn to ACT UP through their interest in art and media. These two major groups of women activists converged in ACT UP's first year and organized important zap actions to counter the AIDS narrative that relegated women to the sides.

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<sup>189</sup> Thomas Morgan, "Mainstream Strategy for AIDS Group," *New York Times*, July 22, 1988, sec. B1.

<sup>190</sup> Ibid., sec. B4.

<sup>191</sup> In addition to the *New York Times*, other publications including the *Village Voice*, ran articles on the Shea Stadium demonstration.

### III. EXPERIMENTATION

Within the context of an apathetic political and social response to the AIDS crisis, ACT UP's activists experimented with a variety of methods to push leaders into action. As Catherine Saalfeld and Ray Navarro would reflect in 1991, "Viruses do not discriminate, people in power do and as they do, they willfully transform a medical emergency into a social and political crisis."<sup>1</sup> Women in ACT UP believed that with political pressure, they could force people in power to adequately respond to the crisis. As ACT UP's membership grew more diverse in 1988, women activists argued that the best way to halt the crisis was to address the underlying issues of sexism, racism, and heterosexism that fed the crisis. While women in ACT UP remained dedicated to distributing safer sex information to protect women from HIV/AIDS, in the fall of 1988, women in ACT UP focused on the larger, institutional causes that prevented people with AIDS from accessing treatment and education. Demands grew less vague, as Maria Maggenti remembered of ACT UP's first actions, as ACT UP focused on specific people in power, policies, and agencies, like the FDA, the CDC, the NIH, and SSA.

Women in ACT UP encouraged this process of experimentation as more diverse women joined the movement. While ACT UP always had a contingent of lifelong activists who understood the power of zap actions and provided a language about patient empowerment, after 1988, different types of women joined the group. Professional

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<sup>1</sup> Catherine Saalfeld and Ray Navarro, "Shocking Pink Praxis: Race and Gender on the ACT UP Frontlines," 342.

women from the medical and legal fields joined the AIDS movement after seeing the discrimination women with AIDS faced firsthand. Meanwhile, they were joined by a much smaller group of poor and working class HIV positive women who knew what women living with AIDS really needed.<sup>2</sup> Together, these different groups of women shattered the façade that women did not have AIDS and created practical, accessible resources for people with AIDS.

While professional women helped ACT UP refine its positions, the smaller, but significant group of working class women who had experience with sex work, drug use, and incarceration also helped shape the group. These women, explored in the following chapter, like Zoe Leonard, Katrina Haslip, and Iris De La Cruz joined ACT UP as members and recruited people from the Gay and Lesbian Community Center and other health activist organizations to increase ACT UP's numbers for these large demonstrations. As a result, some working class women with personal experiences with HIV/AIDS, either through their own exposure or their own diagnosis, taught the members of ACT UP what women with AIDS needed, both practically and politically. In this way, they also refined ACT UP by broadening the scope of the organization to better include the needs of women with AIDS. While professional women brought expert knowledge into ACT UP, working class women brought more practical knowledge and a kind of politics of survival into the group.

From 1988 through 1991, as women in ACT UP tried to push the group to connect the disease to larger issues of oppression, other members in ACT UP pushed

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<sup>2</sup> In *Infectious Ideas*, Jennifer Brier writes that in 1987, ACT UP had six committees, but by 1988, that number had doubled.



back. As Jennifer Brier argues, ACT UP was largely split on the future direction of the group.<sup>3</sup> Members debated whether their time would be best spent staying true to ACT UP's original purpose of increasing availability of AIDS drugs or if the most effective way to tackle the AIDS was to focus on the underlying issues of racism, sexism, classism, heterosexism, and homophobia that fueled the crisis. This dilemma was clear in a 1988 interview with radical newsletter *Resist* with members Steve Bohrer, David Robinson, Maxine Wolfe, and Maria Maggenti. Maxine Wolfe described that "at every meeting," at least one member would object to ACT UP's expanding focus.<sup>4</sup> These members, she argued, tried to keep ACT UP "narrow, narrow, narrow," working solely on "cures."<sup>5</sup> Others, of which she considered herself, tried to teach others to see the "connections between the issues" of, for example, discrimination and AIDS.<sup>6</sup> Maggenti agreed with Wolfe, explaining that "AIDS is a political issue that deserves political analysis and a political response."<sup>7</sup> And while she described feeling out of place as a lesbian in the "predominantly gay male group," Maggenti argued that ACT UP was different in its ability to "get out on the streets."<sup>8</sup> Despite their infighting, she said, ACT UP coordinated actions that gave activists a space for their rage.

In another interview several months later with other members, including founders Vito Russo and ACT UP's first female member Rebecca Cole, Maxine Wolfe continued

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<sup>3</sup> Brier, *Infectious Ideas*, 160.

<sup>4</sup> Published and near Print Material, *Resist*. 1988. MS ACT UP: The AIDS Coalition to Unleash Power: Series X. Published and near Print Material Box 188, Folder 2. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/6AMjf7>. Accessed 20 Mar. 2018.

<sup>5</sup> Ibid.

<sup>6</sup> Ibid.

<sup>7</sup> Ibid.

<sup>8</sup> Ibid.

to make insightful observations about ACT UP's overwhelming white male-ness. Wolfe affirmed Maria Maggenti's argument, saying that when she first attended an ACT UP meeting she felt out of place as a woman in a male group. Answering why she put up with this feeling of discomfort, Wolfe explained that the women of ACT UP "cared and we wanted to do activist work around [women's health]." <sup>9</sup> Rebecca Cole built on Wolfe, arguing that ACT UP did not know how to incorporate the lack of access to healthcare faced specifically by women and people of color. "I think ACT UP, because it's predominantly gay white men, has had a little bit of trouble understanding" the movement for health care, she lamented. <sup>10</sup> Reiterating that the group was "mostly white and mostly male," Cole expressed sadness that her organization did not include more women and people of color in its Coordinating Committee. She offered the explanation that perhaps because "women had been much more political for a much longer period of time, radicalizing themselves," they were more responsive to the needs of others. <sup>11</sup> Vito Russo, frustrated with the conversation, retorted:

I have been involved in gay activism for 20 years, and I have heard the "gay white man" speech more times than I care to remember, and I lost my guilt over it about 20 seconds after 1969... You have to hope other people will do more and urge them to do it. And don't jump off a cliff over it. Relax. It's not a national emergency. AIDS is the national emergency. <sup>12</sup>

As early as 1988, conflict brewed as some of the women in ACT UP desired to widen the membership and causes of ACT UP/NY's while feeling that some of their male

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<sup>9</sup> Ibid, p. 32.

<sup>10</sup> Drew Hopkins and Phil Zwickler, "ACT UP or Acting Out?," *New York Nation*, June 27, 1988, 32.

<sup>11</sup> Ibid., p. 56

<sup>12</sup> Ibid, p. 33.

colleagues were unwilling to take them seriously and see the interconnected nature of homophobia, racism, and sexism.

For several years, however, women in ACT UP worked to combined the more immediate issue of finding a cure and the larger issues preventing marginalized people with AIDS from accessing treatment at the local and federal level. When ACT UP channeled their rage into their first demonstration against the federal government in the fall of 1988, the group targeted the Food and Drug Administration (FDA) for their slow drug approval process and high drug prices. The cost of drugs, members argued, prevented most people with AIDS from accessing any form of treatment.<sup>13</sup> To advertise the demonstration, ACT UP distributed leaflets that explained that Frank Young, Ronald Reagan's appointee as Commissioner of the FDA, "ignored" the availability of potential AIDS drugs while "tens of thousand have suffered or died."<sup>14</sup> Garance Franke-Ruta heard this message at the Gay and Lesbian Community Center and joined in, first "simply in the role of warm body in the background."<sup>15</sup> Franke-Ruta, a seventeen-year-old high school drop out New York native, attended the demonstration more because it was an "adventure" than as a political act.<sup>16</sup> However, at ACT UP, she felt a sense of community like she had never experienced before. At the protest, she recalled, there was a "huge,

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<sup>13</sup> Jean Carlomusto, ACT UP Oral History Project, 27.

<sup>14</sup> Ephemera, Flyers, Handbills by ACT UP, FDA. 1988-1993. MS ACT UP: The AIDS Coalition to Unleash Power: Series XI. Ephemera, Flyers, Handbills by Act Up Box 193, Folder 14. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nU7E4>. Accessed 23 June 2018.

<sup>15</sup> Garance Franke-Ruta, transcript of an oral history conducted in 2007 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2007), <http://www.actuporalhistory.org/interviews/images/ruta.pdf>, accessed June 26, 2017, 6.

<sup>16</sup> *Ibid.*, p. 9.

raucous community of people, who were all, in one way or another, outcasts, and socially isolated, and who, out of that, created a community.”<sup>17</sup> Franke-Ruta was one of 1,200 demonstrators who traveled to Maryland in October 1988 for the protest and the large turnout ensured that ACT UP received media attention.<sup>18</sup>

The media coverage of ACT UP’s FDA demonstration spread ACT UP’s message across the country. In the group’s own estimation, around 2,000 newspapers from across the country featured an article about the demonstration, many of which were the front-page story, including the *Boston Globe*, *Houston Chronicle*, *Miami Herald*, *Atlanta Constitution*, and Baltimore’s *The Sun*.<sup>19</sup> The *Washington Post*, for example, explained that while the FDA had eighty potential drugs stuck in the testing process, while only one drug, zidovudine (AZT) had been approved.<sup>20</sup> Other national papers, like the *Wall Street Journal* and *USA Today*, ran stories about ACT UP. Meanwhile, television news agencies, from ABC, NBC, CNN, Spanish CNN, and FOX covered the protest as ACT UP members gave interviews with morning shows, like “CBS This Morning,” and nightly shows, such as CNN’s “Crossfire.”<sup>21</sup> This widespread media coverage, most of which

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<sup>17</sup> Ibid., p. 10.

<sup>18</sup> Dan Bell, “Storming the FDA: A Power-and-Passion Play,” *Village Voice*, October 25, 1988, sec. 27. Historian Jennifer Brier estimates that there were over 1,500 protestors at the FDA in *Infectious Ideas*, p. 166.

<sup>19</sup> Minutes, ACT UP / NY Minutes, August 1988. Aug. 1988. MS ACT UP: The AIDS Coalition to Unleash Power: Series II. Minutes Box 3, Folder 15. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tMi56>. Accessed 23 June 2018.

<sup>20</sup> Susan Okie, “AIDS Coalition Targets FDA for Demonstration,” *Washington Post*, October 11, 1988, sec. 3.

<sup>21</sup> Minutes, ACT UP / NY Minutes, August 1988. Aug. 1988. MS ACT UP: The AIDS Coalition to Unleash Power: Series II. Minutes Box 3, Folder 15. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tMi56>. Accessed 23 June 2018.

was sympathetic to the group's cause—a first for ACT UP—solidified the group's presence, as they protested the lack of federal response to the AIDS crisis, in the mainstream media.

Members of ACT UP too created their own media about the FDA action. Jean Carlomusto and Gregg Bordowitz filmed the demonstration and created a film, *Seize Control of the FDA*, which gay and lesbian events across New York City screened.<sup>22</sup> The tape was a collaborative effort by DIVA TV members, including Catherine Saalfield, and featured scenes of ACT UP's burning Ronald Reagan effigy and the arrests of over of a hundred demonstrators.<sup>23</sup> Meanwhile, the Women's Caucus and the Majority Action Committee, comprised mostly of men of color, collaborated together and formed WIC/MAC to protest the government's failure to include women of all races and men of color in clinical drug trials.<sup>24</sup> WIC/MAC created a leaflet that highlighted the ways that the FDA represented "institutionalized racism and sexism in the AIDS crisis."<sup>25</sup> The leaflet explained women's exclusion from FDA trials on the basis of sex and that people

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<sup>22</sup> Carlomusto, transcript of an oral history conducted in 2002 by Sarah Schulman, 26.

<sup>23</sup> Actions / Demonstrations / Zaps, FDA Action, Rockville, MD (1 of 3), October 7-20, 1988. October 7-20, 1988. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 13, Folder 17. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nU8h4>. Accessed 4 Feb. 2018.

<sup>24</sup> Catherine Saalfield and Ray Navarro, "Shocking Pink Praxis: Race and Gender on the ACT UP Frontlines," 354. As Jennifer Brier explains in *Infectious Ideas* p. 169, the Majority Action Committee formed as a space for people of color in the "very white group." Their name meant to remind all that the majority of people with AIDS were people of color, despite generally being referred to as "minorities."

<sup>25</sup> Committees, Women's Action Committee (3 of 7), 1987-1989. 1987-1989. MS ACT UP: The AIDS Coalition to Unleash Power: Series VII. Committees Box 73, Folder 3. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nSPE4>. Accessed 4 Feb. 2018.

of color made up less than a quarter of trial participants.<sup>26</sup> The Women's Caucus argued that because FDA trial participants required a primary physician, people in poverty were excluded from trials because they could not afford a primary physician.<sup>27</sup> Lastly, the leaflet informed readers that incarcerated people could not participate in trials, despite their decreased survival time.<sup>28</sup> Together with the Majority Action Committee, Women's Caucus successfully used the FDA action to further their message about sexism and racism.<sup>29</sup>

The demonstration at the FDA earned the group enough media attention that reproductive rights activist and former partner of Marion Banzhaf, Risa Denenberg, began to pay attention to ACT UP. The idea of protesting to encourage clinical testing was entirely foreign to Denenberg, who had previously protested the FDA in the 1970s for "experimentation of drugs on women's bodies."<sup>30</sup> Denenberg spent most of her adult

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<sup>26</sup> Ibid.

<sup>27</sup> Ibid.

<sup>28</sup> Ibid.

<sup>29</sup> Catherine Saalfeld and Ray Navarro argue in "Shocking Pink Praxis: Race and Gender on the ACT UP Frontlines" that WIC/MAC also challenged police brutality in their coalition.

<sup>30</sup> Risa Denenberg, transcript of an oral history conducted in 2008 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2008), <http://www.actuporalhistory.org/interviews/images/denenberg.pdf>, accessed June 26, 2017, 31. As feminists advocated for a safe birth control pill, they publicized the FDA's problematic drug approval process. In *Moving the Mountain* (University of Illinois Press, 1999), Flora Davis argues that the FDA treated women as guinea pigs by approving dangerous medications by relying on a "good faith" process in which the pharmaceutical companies themselves had to report adverse side effects. While millions of women took high-dose birth control pill throughout the 1960s, women were dying of blood clots, and the FDA was slow to react. Only under the pressure of feminist activists in the 1970s and early 1980s did the FDA recall dangerous contraception, like the Dalkon Shield, or alert consumers of potential side effects. By allowing women to continue to take dangerous medications knowing full-well of their side effects, feminists like Denenberg argued that the agency experimented on women.

life as a nurse in a feminist women's health collective and thus had a long-developed understanding of how sexism impeded women's access to health care. Denenberg, a nurse and activist, first became acquainted with injustice as a young Jewish girl growing up in Washington, D.C. Experiencing discrimination firsthand combined with her activist mother's passion for school integration fostered Risa's early taste for activism.<sup>31</sup> Then, in 1968, she had an illegal abortion and nearly bled to death from hemorrhaging a few days after the procedure.<sup>32</sup> Denenberg credits this experience with her "interest in women's health."<sup>33</sup> Greatly influenced by the principle of the women's health movement that "women could be in control of [abortion and birth]," Denenberg earned her license as a registered nurse.<sup>34</sup> Working at a collective feminist women's health center in Florida, Denenberg educated patients on how to use a speculum and how to perform menstrual extractions, a safe abortion method that women could perform without a doctor, as well as providing abortions to women in need once a week.<sup>35</sup> In addition, Denenberg participated in "political work and demonstrations" for safe access to abortion care.<sup>36</sup> However, despite her work, Denenberg felt conflicted as a lesbian providing care for straight women without "taking care of [her]self."<sup>37</sup> After the death of a dear friend and an exhausting legal battle with a competing "more conventional" health center, Risa Denenberg moved from Florida to New York City for a fresh start.<sup>38</sup>

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<sup>31</sup> Ibid., p. 3.

<sup>32</sup> Ibid., p. 8.

<sup>33</sup> Ibid., p. 10.

<sup>34</sup> Ibid.

<sup>35</sup> Ibid., p. 14.

<sup>36</sup> Ibid., p. 15.

<sup>37</sup> Ibid., p. 18.

<sup>38</sup> Ibid., p. 20.

In New York, Denenberg entered a nurse practitioner's program and worked in the Public Health Department performing HIV tests.<sup>39</sup> In a "pivotal" moment, her first positive HIV test was that of a "poor black woman, who was doing crack, and probably selling her body," but who never came back for her results.<sup>40</sup> Denenberg had become friends with the woman, who regularly showed up for care—so when she never returned, Denenberg felt devastated that her friend may soon die, or perhaps that she had already died, from the disease. She became interested in the unique toll that AIDS took on women's bodies and attempted to join the Community Health Project (CHP) in 1988, a clinic focused primarily on sexually transmitted diseases.<sup>41</sup> Denenberg was rejected because they did not have a women's health care program. So when Marion Banzhaf told her about ACT UP, Denenberg was interested.

Risa Denenberg joined ACT UP in the beginning of 1989 at the moment when the women in the group began to really push the organization to address these systematic barriers of poverty, racism, and sexism that prevented women from receiving care and education. To accomplish this, women in ACT UP first had to teach the male members, many of whom were upper or middle class white men, how factors of racism, sexism, and poverty inhibited women's access to AIDS treatment and education. Risa Denenberg, staying true to her roots as a health educator, argued that a teach-in, in which the women of ACT UP provided male members with a basic history of the women's health movement, how AIDS manifested in women, and how the government and medical

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<sup>39</sup> Risa Denenberg and Katie Hedger, "Correspondence with Risa Denenberg," July 24, 2017.

<sup>40</sup> Ibid., p. 21.

<sup>41</sup> Ibid., p. 27.



industry prevented women's treatment, would best serve this purpose. As her first activity within ACT UP Denenberg and the Women's Caucus organized a teach-in in the spring of 1989. "These men," she explained, "despite the fact that they were gay men, felt very privileged, and felt like they could do anything, and didn't have a real sense of history, most of them, of movements or of health movements. And so they were kind of like the blind leading the blind."<sup>42</sup> The purpose of the teach-in was for those who "thought a little more historically," particularly for Denenberg, those who participated in the women's health movement, to teach the men in ACT UP that their fight against AIDS was part of a much longer struggle.<sup>43</sup>

The women in ACT UP soon learned there was very little medical literature on AIDS in women. In preparation for the event, new ACT UP member and librarian Polly Thistlethwaite realized there was "not a hell lot" of literature on AIDS in women. There was "no medical data, just social science books." The organizers of the Teach-In sought to change that. First, Thistlethwaite and Denenberg created a bibliography of the available sources on AIDS in women for the members of ACT UP to read. "We felt like we had issues to push to our male colleagues weren't so informed about," Thistlethwaite explained. They taught the members of ACT UP that "HIV was present in certain communities of women, and we thought that it was important for ACT UP to understand, if not understand and embrace, issues of HIV as they manifested and impacted women."<sup>44</sup> The Teach-In coalition forced the larger body of ACT UP to learn about AIDS in women.

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<sup>42</sup> Ibid., p. 32

<sup>43</sup> Ibid., p. 33

<sup>44</sup> Thistlethwaite, ACT UP Oral History Project, 17.

While for Denenberg, this struggle was most clearly linked to the women's health movement, other leaders of the teach-in, like Marion Banzhaf and Maxine Wolfe, also suggested ACT UP to take lessons from other movements. Banzhaf and Wolfe taught about the Civil Rights movement, the antiwar movement, and other health movements, like those for migrant workers and the gay men and lesbians.<sup>45</sup> The underlying factor that connected these movements to the AIDS crisis, argued the women at the teach-in, was the relationship between oppression and empowerment. Denenberg and the leaders of the teach-in yearned to transfer the language of body empowerment from the women's health movement onto the AIDS crisis. In a compilation of their lessons from the teach-in, the Women's Caucus wrote that members of ACT UP had to remember, "Unless you advocate for it, the system does not provide good health care."<sup>46</sup> The AIDS crisis further affirmed this fundamental argument from the women's health movement.

However, there were aspects from the women's health movement that women in ACT UP did not want to repeat. "The successes and failures of that movement provide valuable lessons for the AIDS movement," Maria Maggenti argued.<sup>47</sup> Of primary concern for many of the women in ACT UP was the heterosexism of the movement. According to Denenberg, straight women had relegated lesbians' health concerns to the periphery by making them "secondary to the glaring needs of heterosexual women."<sup>48</sup> Despite that

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<sup>45</sup> Ibid., p. 33

<sup>46</sup> Maria Maggenti, "The Politics and Practice of the Feminist Health Movement and How It Relates to the AIDS Movement," in *The ACT UP Women's Caucus Women and AIDS Handbook* (New York, NY: AIDS Coalition to Unleash Power, 1989), sec. 4A.

<sup>47</sup> Ibid.

<sup>48</sup> Risa Denenberg, "The Politics and Practice of the Feminist Health Movement and How It Relates to the AIDS Movement," in *The ACT UP Women's Caucus Women and AIDS Handbook* (New York, NY: AIDS Coalition to Unleash Power, 1989), sec. 4B.

“lesbians were the core of many feminist clinics and activist groups” during the health movement, they argued that lesbians’ demands were “left out” of the women’s health movement.<sup>49</sup> As many of the women in ACT UP were lesbians, they wanted to refine the model of the movement to better center lesbian health in the ACT UP.

In addition to fighting heterosexism and increasing the sensitivity of ACT UP efforts to lesbians, women in ACT UP, like Marion Banzhaf, addressed what she saw as a kind of “tokenism” in ACT UP.<sup>50</sup> Rather than having one or two representatives of different racial groups, Banzhaf sought to recruit as many women of color as possible to be members and leaders of ACT UP. Banzhaf, too, saw her efforts as being informed by the limits of previous feminist activism. “Like most white-dominated movements, the feminist health movement, with few exceptions, didn’t get beyond giving lip-service to fighting racism and classism,” she wrote. The members of the Women’s Caucus understood that they needed to create a racially inclusive organization that fostered the participation of women of color and women living in poverty. To combat this racism and

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<sup>49</sup> Ibid. Denenberg’s evaluation of contention between heterosexual women and lesbian women during the women’s health movement can also be seen in Wendy Kline’s *Bodies of Knowledge*. Kline demonstrates that there was considerable tension between the lesbians the heterosexual women who wrote and read the Boston Women’s Health Book Collective’s *Our Bodies, Ourselves*. She points to several instances, including conflicts between the lesbian authors of the 1973 edition’s chapter on lesbians and the larger Collective, the letters from lesbian readers who urged editors to not assume the heterosexuality of the book’s readers, and the transformation of chapter’s content after the contentious 1973 edition. While Kline also shows that the Collective seemed to try to adapt to the needs and demands of lesbians, she also demonstrates that underlying each of these conflicts was an uneasiness and resentment between heterosexual and lesbian women in the production of *Our Bodies, Ourselves*. With that, Denenberg’s claims that lesbians felt left out of the movement that they played an essential role in building appear valid.

<sup>50</sup> Marion Banzhaf, “The Politics and Practice of the Feminist Health Movement and How It Relates to the AIDS Movement,” in *The ACT UP Women’s Caucus Women and AIDS Handbook* (New York, NY: AIDS Coalition to Unleash Power, 1989), sec. 4D.

classism, the Caucus hoped to place women of color in leadership roles instead of falling to tokenism.<sup>51</sup>

The Women's Caucus's demands, from the inclusion of lesbians to women of color, to new forms of outreach and activism that better reached poor women, were received well at first. The men in the audience at the teach-in were excited and interested. "My overall impression," recalled Risa Denenberg, "was that the men that came to it loved it, and felt very grateful for that sharing, and learned from it."<sup>52</sup> Polly Thistlethwaite too remembered the male participants enjoying the teach-in. At one point, perhaps as a joke, Larry Kramer examined an anatomically correct drawing and declared in a campy way to everyone, "Oh, that's where the clit is."<sup>53</sup> The levity of the statement, juxtaposed with the intense subject of women's exclusion from healthcare, left an impression on Thistlethwaite.<sup>54</sup>

Women, like Heidi Dorow who entered ACT UP as a young woman too, responded to the teach-in. A student at a small, wealthy liberal arts college, Hampshire College in Amherst, Massachusetts, Dorow participated in the 1987 March on Washington for Lesbian and Gay Rights. At the demonstration, she was arrested on the steps of the Supreme Court alongside women who were members of the Seneca Women's Encampment for a Future of Peace and Justice and was "completely sold" on civil disobedience.<sup>55</sup> "It was really, really exciting" to hear from the other women

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<sup>51</sup> Ibid.

<sup>52</sup> Thistlethwaite, ACT UP Oral History Project, 35.

<sup>53</sup> Thistlethwaite, ACT UP Oral History Project, 22.

<sup>54</sup> Ibid.

<sup>55</sup> Heidi Dorow, transcript of an oral history conducted in 2007 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University,

arrested with her, Dorow recollected.<sup>56</sup> Upon her release from jail after two days and her return to Massachusetts, Dorow joined a student-worker coalition to advocate for better wages for student workers. There, she met Karen Wolfe, Maxine Wolfe's daughter, who, after learning about Dorow's growing passion for civil disobedience, told Dorow about ACT UP. After the younger Wolfe introduced Dorow to her mother, Maxine Wolfe offered Dorow the opportunity to "intern" for ACT UP for a college course.<sup>57</sup> As a young lesbian, Dorow remembered, she jumped at the chance to work with "all these gay people in the group."<sup>58</sup> She felt invigorated by the members' "anger," and by the fact that "they were actually doing something with it."<sup>59</sup> ACT UP provided Dorow with a place to be out as a lesbian, practice civil disobedience, and develop her political ideology.

The teach-in also helped the members of Women's Caucus prepare the rest of ACT UP for their second anniversary protest of their first Wall Street/Trinity Church protest, in which ACT UP turned their ire towards New York City Mayor Ed Koch.<sup>60</sup> Referred to as Target City Hall, this protest, according to a *Village Voice* article, featured the "usual" demands: anonymous testing, treatment and better housing for people with

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2007), <http://www.actuporalhistory.org/interviews/images/dorow.pdf>, accessed June 26, 2017, 17.

<sup>56</sup> Ibid.

<sup>57</sup> Ibid., p. 21.

<sup>58</sup> Ibid., p. 23.

<sup>59</sup> Ibid.

<sup>60</sup> Actions / Demonstrations / ZAPS, Target City Hall, March 28, 1989. 28 Mar. 1989. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 13, Folder 10. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/69Us33>. Accessed 17 Mar. 2018.

AIDS.<sup>61</sup> However, some of ACT UP's activists had much more specific demands, as the activists in the Women's Caucus and Majority Action Committee revived their coalition, WIC/MAC, for the protest.<sup>62</sup> La Cocina, named because they often met in a kitchen, focused on Mayor Koch's failure to address homeless people living with AIDS and the lack of services for women with AIDS.<sup>63</sup> The other group, Bored of Ed, focused on promoting sex positive safe sex information in public schools.<sup>64</sup> "You've got blood on your hands, Ed Koch," WIC/MAC's leaflet read, decrying the mayor for cutting the city's AIDS budget, denying housing to homeless people with HIV, and underfunding drug treatment and AIDS education programs.<sup>65</sup>

On the morning of March 28<sup>th</sup>, three thousand activists flooded New York's City Hall to decry Mayor Koch's inadequate response to crisis.<sup>66</sup> Outside the building, protestors staged a "60s-style sit down" in the middle of traffic, only to be broken up by over seven hundred police officers outfitted in their protective riot gear.<sup>67</sup> The plan, as remembered by Risa Denenberg, was to get arrested to ensure media coverage.<sup>68</sup> ACT UP's plan worked and over two hundred protestors were arrested.<sup>69</sup> However, the police

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<sup>61</sup> Guy Trebay, "Target Practice: Acting Up at City Hall," *Village Voice*, April 3, 1989, p. 11.

<sup>62</sup> Catherine Saalfield and Ray Navarro, "Shocking Pink Praxis: Race and Gender on the ACT UP Frontlines," p. 358.

<sup>63</sup> Jose Fidelino, ACT UP Oral History Project, 20.

<sup>64</sup> Polly Thistlethwaite, ACT UP Oral History Project, 47.

<sup>65</sup> Ibid.

<sup>66</sup> Guy Trebay, "Target Practice: Acting Up at City Hall," *Village Voice*, April 3, 1989, p. 14.

<sup>67</sup> Ibid.

<sup>68</sup> Risa Denenberg, ACT UP Oral History Project, p. 56.

<sup>69</sup> Actions / Demonstrations / ZAPS, Target City Hall, March 28, 1989. 28 Mar. 1989.

MS ACT UP: The AIDS Coalition to Unleash Power: Series IV.

Actions/Demonstrations/Zaps Box 13, Folder 10. New York Public Library. *Archives of*

pulled aside eighty of ACT UP's female protestors and illegally strip-searched them.<sup>70</sup> "It was purely intimidation," Catherine Saalfield later recalled.<sup>71</sup> One of the women who was strip-searched, Garance Franke-Ruta, was not even eighteen years old at the time she was forced to strip down to her underwear for New York City's police officers.<sup>72</sup> Carlomusto and DIVA TV caught the crime on camera and immediately learned the practical importance of filming ACT UP's demonstrations.<sup>73</sup> Their thirty minute film, *Target City Hall*, contained a segment called "Lesbian Activists Producing Innovative Television," interwove clips from the Women's Caucus's teach-in with the illegal strip search by New York's finest.<sup>74</sup> The purpose of this, Saalfield explained in 1991, was to "insist on the connection between women's body politics and the AIDS activist agenda."<sup>75</sup> Saalfield and the members of DIVA TV encouraged ACT UP's larger body to understand the overlapping tactics and motivations between the women's movement and AIDS movement.

In ACT UP, women who participated in the women's movement like Maxine Wolfe encouraged the younger members like Heidi Dorow to "think about women's issues first" rather than relegating them to the sidelines.<sup>76</sup> To do this, women like Wolfe believed ACT UP needed a formal committee that focused entirely on organizing civil

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*Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/69Us33>. Accessed 17 Mar. 2018.

<sup>70</sup> Garance Franke-Ruta, ACT UP Oral History Project, p. 11.

<sup>71</sup> Catherine Gund, ACT UP Oral History Project, p. 37.

<sup>72</sup> Garance Franke-Ruta, ACT UP Oral History Project, p. 10.

<sup>73</sup> Ibid., p. 12.

<sup>74</sup> Catherine Saalfield and Ray Navarro, "Shocking Pink Praxis: Race and Gender on ACT UP's Frontlines," p. 364.

<sup>75</sup> Ibid.

<sup>76</sup> Heidi Dorow, ACT UP Oral History Project, p. 29.

disobedience. According to Dorow, some members of ACT UP, like Wolfe and Risa Denenberg, “came to ACT UP with political beliefs... [that] they formed before they got there.”<sup>77</sup> Those beliefs combined with women’s passions for “women’s issues” and inspired Dorow to focus on the how the CDC’s problematic AIDS definition negatively inhibited women from accessing care. Together, the women created the Women’s Action Committee (WAC). By coming together with other activists, several who encouraged her to advocate for women with AIDS, Dorow’s political identity evolved. With the friendship and encouragement of Wolfe and WAC, Dorow transformed from someone who “wasn’t the most hardcore political person about women’s issues” to an activist who fought for the women “getting screwed from a couple different angles.”<sup>78</sup> Those angles, Dorow explained, were that “women were dying without having an AIDS diagnosis, and they’re not counted in numbers; and then they’re not getting benefits.”<sup>79</sup> Under the mentorship of Wolfe and Denenberg, Dorow grew into a prominent figure within the Women’s Action Committee.

Through the Women’s Action Committee, Dorow also occasionally collaborated with the reproductive rights group Women’s Health and Mobilization! (WHAM!), which had many members in both ACT UP and WHAM!.<sup>80</sup> In fact, as Tamar Carroll argues, WHAM! modeled their structure and tactics off of ACT UP.<sup>81</sup> One of the founders of WHAM!, Karen Ranspacher, even used ACT UP to provide numbers for WHAM!’s first demonstrations. This partnership was a natural one, according to Ranspacher. “ACT UP

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<sup>77</sup> Ibid.

<sup>78</sup> Ibid., p. 47.

<sup>79</sup> Ibid.

<sup>80</sup> Ibid., p. 31.

<sup>81</sup> Tamar Carroll, *Mobilizing New York*, p. 153.



never debated abortion,” Ramspacher explained, because “there were always overlays between the women’s health movement and ACT UP, because the principles are the same.”<sup>82</sup> Both movements believed that “you can wrest healthcare from the health system” in order to make it “easier for people to access the care they need.” For Ramspacher, these were “feminist principles” that ACT UP “built on” to help “women with AIDS.”<sup>83</sup> It just made sense to Ramspacher and other ACT UP members to work together with WHAM! for demonstrations.

Like many of ACT UP’s other women, Ramspacher was already an activist when she joined ACT UP in 1988.<sup>84</sup> Although she first learned about AIDS as a weekend “club kid” in New York City when she was a student at Cornell University, Ramspacher became a feminist after she transferred to Wellesley College, a prestigious all-girl’s school near Boston. There, she rebuffed the anti-pornography movement that had swept up many feminists in the 1980s. Leading anti-pornography theorist Andrea Dworkin argued that pornography depended upon violent exploitation of the women in the films and that it encouraged sexual violence against women, in particular rape, outside of the films.<sup>85</sup> A pro-pornography feminist, Ramspacher instead argued that, “You could actually be into sex and into porn and a feminist at the same time.”<sup>86</sup>

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<sup>82</sup> Karen Ramspacher, transcript of an oral history conducted in 2008 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University, 2008), <http://www.actuporalhistory.org/interviews/images/banzhaf.pdf>, accessed June 24, 2017,

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<sup>83</sup> Ibid., p. 12.

<sup>84</sup> Ibid., p. 7.

<sup>85</sup> John D’Emilio and Estelle B. Freedman, *Intimate Matters: A History of Sexuality in America* (Chicago ; London: The University of Chicago Press, 2012), 351.

<sup>86</sup> Ramspacher, ACT UP Oral History Project, p. 6.

At Wellesley, Ramspacher was exposed to AIDS through her risky behavior. She “was sleeping with men who were either maybe using drugs or sleeping with other men.” While at first, she “kept getting tested every six months” in order to keep track of her negative status, she was turned away by a nurse threatened to stop providing her with the test unless Ramspacher began to use condoms to protect herself.<sup>87</sup> Upon graduation, Ramspacher moved to New York City again and landed a job as a curator for Dia Art Foundation. Through the foundation, a friend introduced Ramspacher to ACT UP. At the 1988 *Village Voice* awards, Ramspacher met Maxine Wolfe and Marion Banzhaf, who encouraged her to attend meetings at the Gay and Lesbian Community Center.

From her first meeting, Karen Ramspacher demonstrated her commitment to women’s health activism by joining the WAC and planning a major demonstration. As a member of WAC, Ramspacher recalled being taught how to perform menstrual extractions “by some of the women who were in the feminist health movement” in ACT UP.<sup>88</sup> So, when the Cardinal of St. Patrick’s Cathedral, John O’Connor, publicly lambasted safe sex education in public schools, despite the growing risk of AIDS amongst young people, Ramspacher suggested a partnership between ACT UP and WHAM! for a major protest.<sup>89</sup> Through this partnership between WAC and WHAM!, the feminist activists planned one of ACT UP’s largest protests in December of 1989 against their massive target, the Catholic Church—and more specifically, St. Patrick’s Cathedral.

A week before the protest, which ACT UP and WHAM! called “Stop the Church,” they distributed a letter in English and Spanish to the parishioners of St.

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<sup>87</sup> Ibid.

<sup>88</sup> Ibid., p. 10.

<sup>89</sup> Ibid.

Patrick's in order to explain their motivations, perhaps sensing their actions could be controversial. The Cardinal and Archbishop of New York, John O'Connor, served at St. Patrick's and had recently pledged his support to the anti-abortion group Operation Rescue.<sup>90</sup> According to ACT UP, he encouraged "all good Catholics" to join him. This, they argued, compounded with his refusal to allow St. Patrick's church bells to ring alongside New York City's other church bells in remembrance of those lost to AIDS.<sup>91</sup> While these factors were worrisome for ACT UP, the biggest fear of all was Cardinal O'Connor's activity in city politics. The Cardinal, they argued, routinely lobbied against women's access to abortion and safer-sex AIDS education in healthcare facilities and public schools.<sup>92</sup> The letter encouraged St. Patrick's attendees to join them in demonstrating in favor of the separation of church and state.<sup>93</sup>

While it is unlikely any parishioners joined the protest, by ACT UP's count, more than 5,000 people showed up to distribute condoms, sex positive safer sex information, and leaflets outside of the St. Patrick's Cathedral to churchgoers and passersby.<sup>94</sup> One leaflet explained ACT UP and WHAM!'s motives, arguing that the Catholic church used its "immense political power" to prevent women from accessing health care by

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<sup>90</sup> Actions / Demonstrations / Zaps, St. Patrick's Cathedral - Stop the Church, NY (4 of 4), October 1989-December 1992. October, 1989-December, 1992. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 15, Folder 4. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/6AT6s2>. Accessed 20 Mar. 2018.

<sup>91</sup> Ibid.

<sup>92</sup> Ibid.

<sup>93</sup> Ibid.

<sup>94</sup> Jason DeParle, "111 Held in St. Patrick's AIDS Protest," *New York Times*, December 11, 1989. See also ACT UP, "Stop The Church 99," <http://www.actupny.org/YELL/stopchurch99.html>. Accessed March 16, 2018.

condemning abortions and condom use.<sup>95</sup> These actions, the leaflet continued, “ensure the spread of HIV (the virus thought to cause AIDS), deny women control of their bodies and endanger all of our lives.”<sup>96</sup> Through the Stop the Church action, protestors demanded that the Catholic Church have its tax-exempt status revoked, that the Cardinal withdraw support for anti-choice legislation, and that the archdiocese establish a safer-sex education in facilities run by the Church.<sup>97</sup> Despite their large numbers, the protestors did not see any of their demands met.

Several protestors also entered St. Patrick’s Cathedral during mass, in which Mayor Ed Koch was in attendance, and chanted pro-abortion and pro-condom chants, which resulted in a large media backlash against ACT UP.<sup>98</sup> One protestor, as uncovered by Tamar Carroll, even threw a consecrated communion wafer into the ground.<sup>99</sup> Later, Maxine Wolfe recalled that this activist, Catholic Tom Keane may have simply dropped

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<sup>95</sup> Ephemera, Flyers, Handbills by ACT UP, 'St. Patrick's Cathedral Demo'. 1989-1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series XI. Ephemera, Flyers, Handbills by Act Up Box 194, Folder 52. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nUfo5>. Accessed 6 Dec. 2018.

<sup>96</sup> Ibid.

<sup>97</sup> Ephemera, Flyers, Handbills by ACT UP, 'St. Patrick's Cathedral Demo'. 1989-1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series XI. Ephemera, Flyers, Handbills by Act Up Box 194, Folder 52. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nUfo5>. Accessed 6 Dec. 2018.

<sup>98</sup> DeParle, “111 Held in St. Patrick’s AIDS Protest.” In *Mobilizing New York* p. 158, Carroll also argues that this protest resulted in increased police brutality towards ACT UP members. She points that while many demonstrators were raised Catholic and felt a sense of cathartic release from the protest, the police officers felt “emotional” about guarding the Cathedral. After the Stop the Church protest, police responded to protestors more violently, even clubbing one ACT UP member Chris Hennelly in the head, resulting in hospitalization, long-term brain damage, and lifelong seizures. The Stop the Church protest shifted how many New Yorkers viewed ACT UP for the worse.

<sup>99</sup> Carroll, *Mobilizing New York*, 155.

the wafer.<sup>100</sup> Regardless, six activists were arrested and later found guilty of disrupting a religious service.<sup>101</sup> This action resulted in considerable backlash internally and externally against the group. While in a statement to the press, ACT UP members said that the protestors who entered the church “were not trying to deny parishioners’ right to worship,” much of the media’s coverage of the event portrayed the Cardinal O’Connor and his followers as the “real victims.”<sup>102</sup> In a media report, ACT UP members wrote that “the issues we tried to present were largely ignored or distorted, and the Archdiocese did a very good job of diverting the discussion and presenting the church as the victim.”<sup>103</sup> For example, the *New York Post* labeled the activists as violent, unrepentant “militant” who “desecrate[ed] a communion wafer.”<sup>104</sup> Similarly, *Newsday* magazine argued that roughly forty protestors violated the rights of worshippers and used an “inappropriate strategy to publicize their case.”<sup>105</sup> The *Newsday* article even contained a quote from the spokesman for the Coalition for Lesbian and Gay Rights, Andrew Humm, condemning

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<sup>100</sup> Wolfe, ACT UP Oral History Project, p. 79.

<sup>101</sup> Actions / Demonstrations / ZAPS, St. Patrick's Cathedral - Stop the Church, NY (2 of 4), 1990. 1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 15, Folder 2. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/6AT6H2>. Accessed 20 Mar. 2018.

<sup>102</sup> Actions / Demonstrations / Zaps, St. Patrick's Cathedral — Stop the Church, NY (1 of 4), December 6, 1989-September 23, 1990. December 6, 1989-September 23, 1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV.

Actions/Demonstrations/Zaps Box 15, Folder 1. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nUfL4>. Accessed 6 Dec. 2018.

<sup>103</sup> Committees, Media Committee Receipts. 1989. MS ACT UP: The AIDS Coalition to Unleash Power: Series VII. Committees Box 31, Folder 7. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nUg75>. Accessed 25 June 2018.

<sup>104</sup> “No Apology for St. Pat’s Protest,” *New York Post*, December 14, 1989, Series IV, Reel 11, Box 15, Folder 4, ACT UP/NY Archives.

<sup>105</sup> “The ‘Battle’ At St. Pat’s,” *New York Newsday*, December 11, 1989, Folder 3, Bill Bahlman Papers, Central Connecticut State University GLBTQ Archives.

the protest. “I am appalled,” Humm lamented, “that people were stopped from worshipping. There are so many [other] appropriate ways” to protest.<sup>106</sup> Other more salacious publications labeled the coalition “radical,” or as *New York Post* called ACT UP and WHAM!, “homosexual-abortion radicals.”<sup>107</sup> Gay Men’s Health Crisis too issued a statement and called the protest a “mistake,” explaining that the only “winner” of the demonstration was the Church.<sup>108</sup> A rival organization with leaders often butting heads, Gay Men’s Health Crisis certainly had motivation to decry the protest.

However, GMHC’s analysis may not have been far from the truth, for only a one week after the Stop the Church demonstration, ACT UP’s Women’s Action Committee decided to suspend regular meetings for low turn out.<sup>109</sup> While a leading group of women in ACT UP, including Maxine Wolfe who worked with WHAM! to repeat the protest the following year, vehemently supported the Stop the Church action, other activists felt conflicted over their actions. Jamie Bauer, for example, believed the entering the church discounted ACT UP’s message.<sup>110</sup> Internal tension combined with only a third of normal

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<sup>106</sup> Ibid.

<sup>107</sup> Actions / Demonstrations / Zaps, Stop the Church (Pretrial Demo, Other Related Actions). 1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 19, Folder 1. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/6AT675>. Accessed 20 Mar. 2018.

<sup>108</sup> Actions / Demonstrations / Zaps, St. Patrick’s Cathedral - Stop the Church, NY (3 of 4), November 8 1989 - December 7 1990. November 8, 1989-December 7, 1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 15, Folder 3. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5nUfK6>. Accessed 6 Dec. 2017.

<sup>109</sup> Correspondence, ACT UP / NY General Correspondence, 1989. 1989. MS ACT UP: The AIDS Coalition to Unleash Power: Series III. Correspondence Box 8, Folder 4. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5orfF8>. Accessed 4 Feb. 2018.

<sup>110</sup> Bauer, ACT UP Oral History Project, p. 47.

participants regularly attending meetings, the Committee decided to take a “break.”<sup>111</sup> The reason for such low turn out, the report explained, was that most members of WAC were also leading members in other committees, particularly the Women’s Caucus, and thus “no longer ha[d] time to come to WAC.”<sup>112</sup> Instead, members were busy with new projects in other committees, like the Treatment and Data Committee and planning the Albany Action.<sup>113</sup> The unnamed author of the report argued that ACT UP was changing, leaving WAC’s place unsure in the group’s future. “We’re taking a break,” the report explained, “to decide how and if we want to continue in the future as ACT UP becomes more project, rather than committee, oriented.”<sup>114</sup> Despite this insecurity, members certainly did not believe their committee was obsolete, arguing that ACT UP needed a Women’s Action Committee until the group “include[d] issues that specifically address the needs of women with HIV/AIDS in their agenda.”<sup>115</sup> With this statement, the remaining members of WAC made it clear that they did not *want* to disband the committee. However, because most members found projects elsewhere, including in the Women’s Caucus, the Women’s Action Committee had no choice.

One of the projects that many WAC members worked on was a Women’s Caucus demonstration planned on March in Albany, New York to protest the Governor Mario Cuomo’s mishandling of the AIDS crisis in New York. ACT UP argued that Cuomo left

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<sup>111</sup> Correspondence, ACT UP / NY General Correspondence, 1989. 1989. MS ACT UP: The AIDS Coalition to Unleash Power: Series III. Correspondence Box 8, Folder 4. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5orfF8>. Accessed 4 Feb. 2018.

<sup>112</sup> Ibid.

<sup>113</sup> Ibid.

<sup>114</sup> Ibid.

<sup>115</sup> Ibid.

“millions of dollars unspent” in the state’s AIDS budget.<sup>116</sup> This money, they argued, could have created new drug treatment programs, since people with AIDS faced a three to six month wait to enter a program.<sup>117</sup> Governor Cuomo also could have funded more primary healthcare clinics to “serve the needs of both mothers and their young children.”<sup>118</sup> This neglect through under-spending, argued ACT UP, created a crisis in New York. Of the 65,000 New Yorkers lived with HIV/AIDS, many no had health insurance or housing.<sup>119</sup> And instead of spending the entire available budget to fight AIDS in New York, Governor Cuomo left “millions” unspent and planned to cut the state’s AIDS budget for the future.<sup>120</sup>

In response to Governor Cuomo’s plans, ACT UP planned to “shut down the State Capitol” in March of 1990 to demand more drug treatment programs, better housing for people with HIV/AIDS, AIDS programs for incarcerated people, and more health clinics for women and children with AIDS.<sup>121</sup> According to local journalist Kyle Hughes from

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<sup>116</sup> Actions / Demonstrations / Zaps, Albany Action. 28 Mar. 1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 16, Folder 2. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5ormy3>. Accessed 25 Jan. 2018.

<sup>117</sup> Actions / Demonstrations / Zaps, Demonstrations, Albany. 1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 16, Folder 8. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5pVP31>. Accessed 23 Jan. 2018.

<sup>118</sup> Ibid.

<sup>119</sup> Actions / Demonstrations / Zaps, Albany Action. 28 Mar. 1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 16, Folder 2. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5pVNj8>. Accessed 23 Jan. 2018.

<sup>120</sup> Ibid.

<sup>121</sup> Actions / Demonstrations / Zaps, Demonstrations, Albany. 1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 16, Folder 8. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5pVP31>. Accessed 23 Jan. 2018.



the *Birmingham Press & Sun*, an “army” of more than 700 protestors descended upon the Capitol building.<sup>122</sup> Garance Franke-Ruta, who had joined ACT UP to participate in the FDA demonstration in 1988, wrapped the front gates of the Governor’s mansion in “yards of red tape.”<sup>123</sup> The tape, she explained to Hughes, represented the “bureaucracy that has kept my friends waiting for help.”<sup>124</sup> Meanwhile, Risa Denenberg earned media attention when she spray-painted “ACT UP, Fight AIDS” on the Capitol building.<sup>125</sup> While Denenberg later recalled that spray-painting the federal building was “a dumb thing to do,” but that the spirit of the demonstration swept her up.<sup>126</sup> During her arrest, and the arrests of more than fifty demonstrators, police wore latex or leather gloves and were accused of unnecessarily rough arrests.<sup>127</sup> While the demonstrators practiced nonviolence, the police did not do the same.

ACT UP protestors had similar interactions with the police at their next major protest when over eighty demonstrators were arrested at the “noisy but peaceful demonstration” at the National Institute of Health in May of 1990.<sup>128</sup> Karen Ramspacher was one of the organizers of the demonstration, called “Storm the NIH.”<sup>129</sup> She later recalled, “We were storming the NIH for all the people that couldn’t stand up for themselves, so it’s the poor who weren’t getting access to care, and women who were

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<sup>122</sup> Kyle Hughes, “Protestors Force AIDS Issue on Capitol,” *Birmingham Press & Sun*, March 29, 1990, sec. A1.

<sup>123</sup> Ibid.

<sup>124</sup> Ibid.

<sup>125</sup> Ibid.

<sup>126</sup> Denenberg, ACT UP Oral History Project, 55.

<sup>127</sup> Kyle Hughes, “Protestors Force AIDS Issue on Capitol,” *Birmingham Press & Sun*, March 29, 1990, sec. A1.

<sup>128</sup> Veronica T. Jennings and Malcom Gladwell, “1,000 Rally for More Vigorous AIDS Effort,” *Washington Post*, May 22, 1990, sec. A1.

<sup>129</sup> Ramspacher, ACT UP Oral History Project, 33.

being denied participation in clinical drug trials.”<sup>130</sup> Over eighty demonstrators were arrested, twenty of which were women led by Maxine Wolfe who had taken over the office of the director of the NIH’s AIDS division, Dr. Daniel Hoth, in order to convince him to hold an NIH-sponsored conference specifically on women with HIV/AIDS.<sup>131</sup> In the office, some protestors sat down in order to crowd the office, while others, including Wolfe, went through Dr. Hoth’s cabinets to place ACT UP flyers in “every file cabinet there.”<sup>132</sup> Meanwhile, outside the building, Karen Ramspacher and several of the women who participated in both ACT UP and WHAM! called themselves “Invisible Women” and wrapped themselves in gauze to bring attention to the women with AIDS who were largely invisible in the crisis.<sup>133</sup>

Many of the members of the Women’s Caucus were interested in producing more than just zap actions. After the success of the Teach-In in March of 1989 and the serious lack in literature, several women in ACT UP wanted to publish a book. The book, which historian Tamar Carroll demonstrates was modeled after *Our Bodies Ourselves*, would shine a light on women with AIDS and the struggles they faced when attempting to receive health care.<sup>134</sup> Unlike the first edition of *Our Body Ourselves*, however, this book would include the voices of a variety of women. When Risa Denenberg and others prepared for their teach-in during the previous year, they realized that in addition to little

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<sup>130</sup> Ibid.

<sup>131</sup> Actions / Demonstrations / Zaps, NIH. 21 May 1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series IV. Actions/Demonstrations/Zaps Box 16, Folder 11. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/56dW28>. Accessed 8 Aug. 2017.

<sup>132</sup> Wolfe, ACT UP Oral History Project, 87.

<sup>133</sup> Ramspacher, ACT UP Oral History Project, 34.

<sup>134</sup> Tamar Carroll, *Mobilizing New York*, p. 152.

medical literature, there was also serious lack of educational materials for women on AIDS. In an effort to correct this, a diverse group of women in ACT UP set out to research and write chapters to contribute. The purpose of the book, called *Women, AIDS, and Activism*, was to “advance research by and about women in the AIDS crisis, provide information about women’s particular needs, analyze the impacts of AIDS on women’s lives from a feminist perspective, and promote grassroots activism.”<sup>135</sup> Published in the summer of 1990, the book was the first to discuss both political and health care aspects of the AIDS crisis for all women, while still placing racism as the central analytic lens of the book.<sup>136</sup> In a way, *Women, AIDS, and Activism* was a response to Evelyn Hammonds’ call for activists to address the full spectrum of factors that prolonged the AIDS crisis. Instead of only examining the role of political activism on behalf of white activists, the contributors elevated other voices, particularly women of color, who faced the brunt of discrimination in receiving AIDS education and treatment.

The Women and AIDS Book Group, led by Marion Banzhaf, recognized that poor women needed to be able to purchase the book and thus set the price below production cost. For those women who still could not afford the book, the group members shipped free copies to women’s groups across the country. “The response to this handbook that we had made was really overwhelmingly positive. We were getting requests from around

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<sup>135</sup> Marion Banzhaf, ed., *Women, AIDS and Activism* (Boston, MA: South End Press, 1990), vii.

<sup>136</sup> Banzhaf, ACT UP Oral History Project, 82. Jennifer Brier argues that in placing race as a central tenet of the book, the Women and AIDS Book group echoed the work of the Majority Action Committee in *Infectious Ideas* p. 176. These efforts, Brier continues, followed in the footsteps of AIDS advocates working in the global South who situated economic equality as the means to eradicate AIDS.

the country and within the group. Everyone wanted a copy of this handbook.”<sup>137</sup> It was vital to Marion Banzhaf that women with AIDS could access the book. To distribute the book and its information as quickly as possible, the editors sought out gay publishing houses with which ACT UP already had a connection. They settled upon South End Press in Boston because as a nonprofit, the publisher allowed the women to set the price below the cost of production at seven dollars per book.<sup>138</sup> And for women who could not afford the book, the editors and authors “gave away a lot of copies. I had boxes of them and would ship them for free,” contributor Polly Thistlethwaite recalled.<sup>139</sup> And to keep the chapters as authentic as possible, Banzhaf asked women with personal experiences with AIDS to contribute chapters.

Banzhaf showcased the voices of marginalized women in the book because women were experts in their own rights through their unique experiences with AIDS. For example, ACT UP member Zoe Leonard, a former sex worker and drug user, wrote the chapter intended to educate sex workers on safer sex and condom negotiation. Leonard used her experiences selling sex to teach women practical ways to demand condom use. She also argued that sex workers had been “scapegoated” as “pools of contagion, reservoirs of infection, and vectors of transmission.”<sup>140</sup> Because of this scapegoating, sex workers were at an increased risk of violence from clients who demand condom-less sex and police who confiscate bleach and condoms from suspected sex workers.<sup>141</sup> To rectify

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<sup>137</sup> Thistlethwaite, ACT UP Oral History Project, 21.

<sup>138</sup> Polly Thistlethwaite, ACT UP Oral History Project, 27.

<sup>139</sup> Ibid.

<sup>140</sup> Zoe Leonard and Polly Thistlethwaite, “Prostitution and HIV Infection,” in *Women, AIDS and Activism* (Boston, MA: South End Press, 1990), 179.

<sup>141</sup> Ibid, p. 183.

this, Leonard encouraged AIDS activists to collaborate with sex-workers-rights organizations and sex workers to organize safer-sex education efforts, along with fighting the state for exposing sex workers to violence through confiscation of prophylaxis.<sup>142</sup>

This was not Zoe Leonard's first safer-sex outreach effort. When she joined ACT UP in 1988, Leonard argued that young queer teens had an increased risk of using intravenous drugs and that they would eventually turn to sex work to sustain their addictions. To combat this, she got together with a group of other new members, including Catherine Saalfeld, and planned outreach for "queer teens [who were] more likely to use drugs" and like herself, used sex work to earn money to buy drugs.<sup>143</sup> In gentrified New York City, many people living in the Lower East Side were consumed by drug addiction.<sup>144</sup> Leonard believed that successful AIDS outreach needed to combine safer sex information and information on the transmission of AIDS through sharing needles.<sup>145</sup>

Under the mayorship of conservative Ed Koch, Leonard recalled, activists faced an uphill battle in establishing needle exchanges.<sup>146</sup> Leonard recalled later that Mayor Koch did not consider needle exchanges a legitimate means to tackle the public health issues of drug use and AIDS.<sup>147</sup> Despite the risk of arrest for distributing drug paraphernalia, Leonard set up needle exchange sites across the city, tables with "hundreds

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<sup>142</sup> Ibid, p. 184.

<sup>143</sup> Zoe Leonard, ACT UP Oral History Project, 27.

<sup>144</sup> Ibid.

<sup>145</sup> Ibid., p. 30.

<sup>146</sup> Ibid., p. 27.

<sup>147</sup> Ibid.

and hundreds and hundreds of packets” of needles, condoms, bleach, and water.<sup>148</sup>

Staffed by members of ACT UP, Leonard and her group also “answer[ed] questions that they might not be able to ask anywhere because there was no public sex education and anything about public sex health.”<sup>149</sup> Leonard wanted to expose the “systematic negligence” that led people to believe AIDS only affected gay men and left anyone else outside of outreach by making “this part of ACT UP’s agenda.”<sup>150</sup> She carried this passion on in her contribution to *Women, AIDS, and Activism*.

*Women, AIDS, and Activism* also included chapters written by incarcerated women with AIDS, thanks to Marion Banzhaf’s connection with Bedford Hills Correctional Facility in upstate New York.<sup>151</sup> Through her partner, Banzhaf knew Judy Clark and Kathy Boudin, members of the SDS and Weather Underground who were serving time for a 1981 robbery and murder.<sup>152</sup> Clark and Boudin were members of an AIDS support and education group inside Bedford Hills called AIDS Counseling and Education (ACE).<sup>153</sup> Katrina Haslip, an incarcerated Muslim woman of color with AIDS, founded ACE to combat the oppression and loneliness that incarcerated women with

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<sup>148</sup> Ibid. Historian Cathy J. Cohen has pointed to ACT UP’s increased efforts in needle exchange and prison outreach programs as moments of possibility in which people from a variety of backgrounds, “heterosexual, gay, poor, wealthy, white, black, Latino,” converged to “challenge dominant constructions of who should be allowed and who deserved care.” These were moments of unity in which marginalized people took on the status quo in a way that, according to Cohen, demonstrates the potential for ACT UP to embrace a queer, rather than gay, politics based on the marriage of sexual fluidity and radical politics in “Punks, Bulldaggers, and Welfare Queens: The Radical Potential of Queer Politics?,” *GLQ: A Journal of Lesbian and Gay Studies* 3 (May 1997): 437–65.

<sup>149</sup> Ibid., p. 28.

<sup>150</sup> Ibid., p. 29.

<sup>151</sup> Banzhaf, ACT UP Oral History Project, 42.

<sup>152</sup> Ibid.

<sup>153</sup> Ibid., p. 43.

AIDS felt.<sup>154</sup> The women of ACE argued to Banzhaf that women with AIDS were “the most oppressed in the prison. They were the most stigmatized. They were the most hated.”<sup>155</sup> ACE provided women with support in response to this reality.

In their chapter for *Women, AIDS, and Activism*, the women of ACE, including Kathy Boudin, Judy Clark, and Katrina Haslip, explained why they founded ACE and highlighted the unique issues women in prison faced. “Prior to the formation of ACE,” the women wrote, “Bedford was an environment of fear, stigma, lack of information, and evasion.”<sup>156</sup> Incoming inmates were subjected to mandatory testing and quarantine if they were found to be HIV positive.<sup>157</sup> This quarantine, ACE argued, was a “punitive” measure that denied women access to the “law library, jobs, education, recreation, visitation, and the canteen.”<sup>158</sup> In response, five women formed ACE to establish peer education, become medical advocates for each other and other women in Bedford with HIV/AIDS, and provide emotional support for one another.<sup>159</sup> ACE gave women “hope that has strengthened us and... broken our silence.”<sup>160</sup> Women in ACE also argued that incarcerated women with AIDS faced the same problems with women with AIDS on the outside faced and then some, due to the racism and discrimination that incarcerated women faced.

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<sup>154</sup> Ibid., p. 46.

<sup>155</sup> Marion Banzhaf, ACT UP Oral History Project, 44.

<sup>156</sup> Kathy Boudin, Judy Clark, and Katrina Haslip, “Voices: Women of ACE (AIDS Counseling and Education), Bedford Hills Correctional Facility,” in *Women, AIDS and Activism* (Boston, MA: South End Press, 1990), 143.

<sup>157</sup> Ibid, p. 143.

<sup>158</sup> Ibid, p. 140.

<sup>159</sup> Ibid., p. 148

<sup>160</sup> Ibid, p. 155.

Iris De La Cruz was a member of both ACE and ACT UP who used her experiences with sex work and drug use to broaden the understanding of AIDS for the women in ACT UP who did not have the virus.<sup>161</sup> De La Cruz, who referred to herself as “Iris with the Virus,” did this through her writing. After serving time at Bedford Hills with Katrina Haslip, she collaborated with ACT UP in their publication of the activist guidebook *Women, AIDS, and Activism*. The book, written and edited by members and former members of the Women’s Caucus provided readers with information on women’s risks, as well the stories of activists and their successful techniques. In De La Cruz’s chapter, a memoir, she explained that while her first introduction to activism was through the Puerto Rican Socialist Party, she was particularly interested in sex workers’ rights.<sup>162</sup>

De La Cruz used sex work to maintain both her addiction to heroin, as well as provide for her young daughter. She enjoyed her work, describing the “feeling of power” she got when male clients inquired about her services.<sup>163</sup> De La Cruz began to write about her experiences in the mid-1970s, selling articles to men’s magazines about sex and drugs. Through her writing job, De La Cruz met a fellow sex worker who wanted to “revive” the sex workers advocacy group Prostitutes of New York (PONY).<sup>164</sup> De La Cruz became interested in AIDS activism while she worked as a spokesperson for PONY

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<sup>161</sup> Terry McGovern, ACT UP Oral History Project, 20.

<sup>162</sup> Iris De La Cruz, “An Excerpt from ‘Sex, Drugs, Rock-N-Roll, and AIDS,’” in *Women, AIDS and Activism* (Boston, MA: South End Press, 1990), 131.

<sup>163</sup> Ibid.

<sup>164</sup> Ibid. Melinda Chateaufort writes that PONY was formed in 1976 to protect the sex workers who were affected by the effort to “clean up” Times Square in *Sex Workers Unite: A History of the Movement from Stonewall to SlutWalk* (Beacon Press, 2014) and revived by Iris De La Cruz in 1980. See also Ronald Weitzer’s 1991 article “Prostitutes Rights in the United States: The Failure of a Movement,” *The Sociological Quarterly* 32, no. 1 (March 1991): 23–41.



because she “started noticing that a lot of [her] friends were getting sick and dying.”<sup>165</sup> This realization fostered a rage within her, and De La Cruz was arrested for stabbing a client in the eye after he tried to “rip [her] off.”<sup>166</sup> While in prison, De La Cruz grew ill and realized that she too had the virus. Instead of turning to violence again, De La Cruz “channeled [her] rage [through] loving support groups.”<sup>167</sup> The most meaningful of these groups was ACE.

Through ACE, De La Cruz met other women with AIDS. “I felt like I was the only woman in the world with AIDS. It was all gay men,” she recalled. “This group changed that.”<sup>168</sup> Meeting other women with AIDS also encouraged De La Cruz to create a support group for bisexual and heterosexual mothers with AIDS. Her motivation, she explained was simply that she was “tired of [her] people being neglected and left dying on the streets.” Through her work in this support group, Iris De La Cruz realized that black and Puerto Rican mothers living in poverty had very little access to AIDS education and hoped to change that through her activism with ACE and ACT UP.<sup>169</sup>

Marion Banzhaf also argued that racism conflated with other factors to inhibit women’s access to AIDS care and that activists had to demonstrate a dedication to fighting racism as well as AIDS. Banzhaf argued that AIDS was only the most recent instance of poor medical treatment for people of color. “A common adage in the Black community,” she explained, “is, ‘when white people get a cold, black people get

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<sup>165</sup> Ibid., 131.

<sup>166</sup> Ibid., 132.

<sup>167</sup> Ibid., 132.

<sup>168</sup> Ibid., 133.

<sup>169</sup> Ibid.

pneumonia.”<sup>170</sup> Black people had cancer, diabetes, heart disease, and infant mortality at higher rates than white people, Banzhaf argued, and AIDS was no exception. In 1990, AIDS was the leading cause of death of young women, and seventy-three percent of those women were women of color.<sup>171</sup> This longer history of medical neglect of people of color was American tradition, argued Banzhaf. “The United States has historically enacted policies of health care discrimination and outright genocide,” she wrote.<sup>172</sup> Citing pox-infested blankets, mass sterilizations of black and Puerto Rican women, and the presence of heroin in black neighborhoods in the 1960s, Banzhaf argued that the government again implemented “discriminatory policies” in its response to AIDS.<sup>173</sup> In response to this discrimination, AIDS activists, who were largely white, needed to build coalitions with people of color to create a “stronger base that has more potential to win change.”<sup>174</sup> Banzhaf called for all people affected by the AIDS crisis to band together in order to create more change.

In addition, Marion Banzhaf encouraged AIDS activists to continue to build coalitions with reproductive rights activists in a chapter written by her, Karen Ramspacher and another WHAM! founder and ACT UP member, Tracy Morgan. The women’s health movement of the 1970s, they argued, “confronted the medical establishment as an industry that was sexist, racist, and classist in its treatment of

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<sup>170</sup> Marion Banzhaf, “Race, Women, and AIDS: Introduction,” in *Women, AIDS and Activism* (Boston, MA: South End Press, 1990), 81.

<sup>171</sup> Ibid., p. 81.

<sup>172</sup> Ibid., p. 81.

<sup>173</sup> Ibid., p. 82.

<sup>174</sup> Ibid.

women.”<sup>175</sup> The AIDS movement developed on that foundation. However, the movement also had to be better than the groups of women’s movement of the 1970s who largely “represent[ed] the interests of white middle-class women” by focusing primarily on abortion rights.<sup>176</sup> Not enough groups, Banzhaf, Ramspacher, and Morgan wrote, also included causes that mattered to communities of color, like sterilization.<sup>177</sup> Likewise, AIDS activism took place largely in the “economically advantaged, white gay male community.”<sup>178</sup> Activists, then, needed to learn from the mistakes of the 1970s and broaden their platform. In order to do this, the authors argued, “women’s issues must become part of all activists’ demands where treatment and drugs are concerned.”<sup>179</sup> One of these issues was more targeted outreach for different communities women who were otherwise largely neglected, like immigrants and lesbians.

Haitian immigrants in particular were in need of outreach that took into account their cultural differences, argued *Women, AIDS and Activism* contributor Yannick Durand. Durand and ACT UP’s Alexandra Juhasz worked with the Brooklyn AIDS Task Force (BATF), an “under-funded social service organization—staffed entirely by black women” that helped poor people living with AIDS.<sup>180</sup> As historian Julio Capó Jr. argues, Haitians were part of the “‘4-H’ club,” groups of people thought to have higher risk for

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<sup>175</sup> Marion Banzhaf, Tracy Morgan, and Karen Ramspacher, “Reproductive Rights and AIDS: The Connections,” in *Women, AIDS and Activism* (Boston, MA: South End Press, 1990), 199.

<sup>176</sup> *Ibid.*, p. 201.

<sup>177</sup> *Ibid.*

<sup>178</sup> *Ibid.*

<sup>179</sup> *Ibid.*, p. 202.

<sup>180</sup> *Ibid.*, p. 44.

HIV.<sup>181</sup> Because of this association between ethnicity and AIDS, Capó explains, Haitian people in the United States experienced heightened discrimination and prejudice.<sup>182</sup>

Many of the women who used the Brooklyn AIDS Task Force for health services and education were Haitian immigrants who were entirely unfamiliar with the disease and the services they could access because of it. Durand explained, “For Caribbean women, their culture does not allow them to as assertive as the American health system requires.”<sup>183</sup> A native Haitian herself, Durand further elaborated that reluctance to be assertive with doctors “had nothing to do with class; it’s a frame of mind.”<sup>184</sup> Because of this, BATF offered Haitian women with AIDS education on how to navigate the health care system in the United States. As a member of the same culture, Durand understood that Haitian women would not use the “buddy system” that became popular amongst feminists.

Already wary of being controlled or manipulated, Haitian immigrants would not feel comfortable bringing an advocate with them to appointments. Instead, BATF gave women “information and tr[ie]d to empower them to make their own decisions.”<sup>185</sup>

Despite its focus on women immigrants from Haiti, BATF also tried to reach a wide group of people.<sup>186</sup> By hiring staff members who “represent[ed] various cultures, sexual orientations, and both genders,” BATF hoped to target the “people [who were] totally left

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<sup>181</sup> Jonathon Bell et al., “Interchange: HIV/AIDS and U.S. History,” *The Journal of American History* 104, no. 2 (September 2017): 441. The other “h” groups in the “4-H club” were homosexuals, heroin and other intravenous drug users, and hemophiliacs.

<sup>182</sup> Ibid.

<sup>183</sup> Yannick Durand, “Cultural Sensitivity in Practice,” in *Women, AIDS and Activism* (Boston, MA: South End Press, 1990), 85.

<sup>184</sup> Ibid.

<sup>185</sup> Ibid., p. 85.

<sup>186</sup> Ibid., p. 89.

out by the experts.”<sup>187</sup> Durand, Alexandra Juhasz, and the other members of the Brooklyn AIDS Task Force served those who were rendered invisible in the AIDS crisis.

Jean Carlomusto argued that lesbians too were invisible and that video was a way to reach women with sex positive safer-sex education. In addition to her pieces with ACT UP on the *Cosmo* action, Carlomusto created a series of safer-sex shorts “to get the message out that safer sex can be hot.”<sup>188</sup> In one of the shorts, titled *Current Flow*, Carlomusto embraced a more erotic form of safer sex information in order to gain a wider audience of women. This video, Carlomusto wrote, blended “advertisement, music video, and pornography.”<sup>189</sup> Carlomusto purposefully featured an interracial cast that included a butch lesbian of color and a white sex worker “graphically” using dental dams and latex gloves as barrier methods for sex that was both safe and erotic.<sup>190</sup> Carlomusto targeted lesbians, particularly lesbians of color, because lesbians and women of color were largely left out of the safer sex conversation, as public perception still labeled AIDS as a white gay man’s disease.

Through the publication of *Women, AIDS and Activism*, the book’s contributors had accomplished the tasks of both “challeng[ing] assumptions about how women were affected by HIV infection and fight[ing] the invisibility of women in the AIDS crisis.”<sup>191</sup> This book quickly became the most cited book published on women and AIDS.<sup>192</sup> The

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<sup>187</sup> Ibid., p. 90.

<sup>188</sup> Jean Carlomusto, “Focusing on Women: Video as Activism,” in *Women, AIDS and Activism* (Boston, MA: South End Press, 1990), 216.

<sup>189</sup> Ibid.

<sup>190</sup> Ibid.

<sup>191</sup> Marion Banzhaf, ed., *Women, AIDS and Activism* (Boston, MA: South End Press, 1990), vii.

<sup>192</sup> Brier, *Infectious Ideas*, 175.

variety of content and authors in the book represented editor Marion Banzhaf's desire to open AIDS activism up to "the people most affected."<sup>193</sup> The end result was, according to one reviewer, the founding president of the National Black Women's Health project Byllye Y. Avery, a "powerfully diverse, informative, and comprehensive patchwork of ideas, experiences, and emotions of women who live and know the reality of AIDS."<sup>194</sup> The book had a lasting impact, according to Banzhaf, who argued that it "remains a singular, stellar book in the canon, the first book about women and AIDS that included both a political analysis and a healthcare analysis."<sup>195</sup> *Women, AIDS, and Activism* reached underserved communities with accurate and inspiring information about the AIDS crisis, while encouraging activists who build coalitions with other organizations. The book was more successful at reflecting the wide range of experiences, and a number of different life experiences than the editors' experiences in ACT UP.

One of the most powerful coalitions women built during the AIDS crisis was that between ACT UP, ACE, and the HIV Law Project, facilitated by Katrina Haslip. Haslip, one of the founders of ACE and member of ACT UP, sat on the board of the HIV Law Project and brought the groups together to solve the legal discrimination against women with AIDS.<sup>196</sup> McGovern, a housing lawyer, met Haslip when she began to take referrals from the Women's Prison Association in 1989.<sup>197</sup> Her clients all praised Haslip's work

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<sup>193</sup> Banzhaf, ACT UP Oral History Project, 81.

<sup>194</sup> Marion Banzhaf, ed., *Women, AIDS and Activism* (Boston, MA: South End Press, 1990), back cover.

<sup>195</sup> Banzhaf, ACT UP Oral History Project, 82.

<sup>196</sup> Gund, ACT UP Oral History Project, 46.

<sup>197</sup> Terry McGovern, transcript of an oral history conducted in 2007 by Sarah Schulman, ACT UP Oral History Project (Cambridge: Harvard University,

inside Bedford, leading McGovern to reach out to her after hearing that women had trouble qualifying for benefits because they did not meet the CDC's definition of AIDS.<sup>198</sup> Already an occasional attendee at ACT UP meetings, McGovern began to formulate a plan to challenge the CDC's definition by suing the Social Security Administration for discriminating against women. With the help of Risa Denenberg's medical background, McGovern reviewed women's charts and saw that while women had severe HIV-related illnesses, they could not receive Social Security Administration benefits because they did not technically have AIDS.<sup>199</sup> Because the Administration used the CDC's exclusionary definition, McGovern tried to force a change in both agencies with her lawsuit. In doing so, she combined the activism of ACT UP, her legal expertise, and the discrimination faced by women in ACE that prevented them from accessing their rightful benefits.<sup>200</sup>

Terry McGovern did not graduate law school with the idea of helping women with AIDS get their rightful social security benefits. While attending Georgetown, she interned for the Federal Defenders of San Diego. Working on the border of Tijuana and San Diego, McGovern worked to defend people who were caught on between the two country's legal systems. Her work there "changed [her] whole path," and after graduation, McGovern took advantage of a Carter-era program to provide legal help for

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2007), <http://www.actuporalhistory.org/interviews/images/mcgovern.pdf>, accessed June 26, 2017, 17.

<sup>198</sup> Ibid., p. 16.

<sup>199</sup> Risa Denenberg and Katie Hedger, "Correspondence with Risa Denenberg," July 24, 2017.

<sup>200</sup> Ibid., p. 18.

“people who were under the National Poverty Index.”<sup>201</sup> While she was hired as a housing lawyer, McGovern’s identity as a single lesbian in an office of men changed this path. As more clients with HIV/AIDS sought legal services, McGovern’s colleagues pushed those cases on to her for fear of catching the illness. “I can’t take it,” they would explain to her. “I have a family.”<sup>202</sup> Despite her coworkers’ attitudes towards her clientele, McGovern took the cases because “the poverty law community certainly failed these folks.”<sup>203</sup> While still technically working as a housing lawyer, McGovern began to build a community of poor people living with AIDS in desperate need of legal counseling.

This community led McGovern to ACT UP. McGovern’s clients were often people who lived in public housing and because of their sexual identity, were not able to include their significant other on their lease. As partners began to fall ill from complication from AIDS, lovers began to get evicted. However, as McGovern saw firsthand, the surviving lovers “were also extremely ill.”<sup>204</sup> She was shocked to see landlords evict sick people who had nowhere else to live. “I was seeing the HIV lens, the poverty lens of HIV, which had everything to do with homophobia and sexism,” McGovern explained.<sup>205</sup> When one of her clients told her about his participation with ACT UP, McGovern curiously attended a meeting. There, McGovern heard from more women who were dying, but did not qualify as having AIDS. Together with the Women’s

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<sup>201</sup> Ibid., p. 11.

<sup>202</sup> Ibid., p. 12.

<sup>203</sup> Ibid., p. 13.

<sup>204</sup> Ibid., p. 13.

<sup>205</sup> Ibid., p. 13.



Caucus of ACT UP, they created a “joint effort” to change the definition.<sup>206</sup> “I was always very clear that a lawsuit was never going to be enough if there wasn’t this massive community organizing and it wasn’t done in the context of activism,” McGovern elaborated. “Because basically, nobody cared, otherwise.”<sup>207</sup> She used the power of ACT UP to bolster her case.

In order to spread awareness about their lawsuit and the CDC and SSA’s discrimination, McGovern and Maxine Wolfe invited thirty of McGovern’s plaintiffs, including Katrina Haslip and Iris De La Cruz, to demonstrate at the Health and Human Services office in October 1990 alongside two hundred protestors.<sup>208</sup> As Jennifer Brier points out, the women with HIV at the protest led to the rest of ACT UP, to the extent that the notoriously raucous group would hush to hear women like Katrina Haslip and Iris De La Cruz speak.<sup>209</sup> McGovern and her colleagues in ACT UP organized busses and speakers. At the protest, women held signs that read “Dead But Not Disabled” to showcase that women often died of AIDS before ever qualifying for disability benefits.<sup>210</sup> Other women carried “signs shaped like tombstones bearing the names of opportunistic infections not recognized as disabling or AIDS-related by the SSA,” participant and ACT UP/DC member Lorrie Sprecher wrote.<sup>211</sup> Women died six times faster than men, Sprecher continued, and could not “afford to wait” on their disability benefits.<sup>212</sup>

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<sup>206</sup> Ibid., p. 21.

<sup>207</sup> Ibid., p. 21.

<sup>208</sup> Ibid.

<sup>209</sup> Jennifer Brier, *Infectious Ideas*, p. 174.

<sup>210</sup> Ibid., p. 34.

<sup>211</sup> Lorrie Sprecher, “Cash Not Caskets: Women With AIDS Dead But Not Disabled,” *ACT UP/DC Frontlines*, November 1990, 1.

<sup>212</sup> Ibid.

Meanwhile, Members of the Women's Caucus covered the HH's sign with black fabric stitched with the message, "Secretary Sullivan: take a memo: women are dying. P.S. Get us coffee."<sup>213</sup> The demonstration resulted in the arrest of eighteen women, one of whom was "grabbed around the throat" by an arresting officer who refused to provide activists with his badge number.<sup>214</sup>

Their demonstration also earned McGovern's lawsuit front-page articles in the *USA Today* and *New York Newsday* and a smaller feature in the *New York Times* as a result, women and AIDS groups across the country called McGovern's office.<sup>215</sup> "A lot of little positive women's groups wanted information... The definition was also used in all the local programs for you to get local benefits of the gateway to housing for people with AIDS; it was used everywhere."<sup>216</sup> As groups began to follow McGovern's case closely and awareness spread amongst political organizations, the lawsuit "got a lot of medical support."<sup>217</sup> The American Medical Association, of which members argued that "the very factors that [led] to the exclusion or underrepresentation of women [in medicine] are evidence of the importance of including them" in all medical research, joined along with 300 other medical and social organizations.<sup>218</sup> Some of the larger organizations that participated with McGovern in the lawsuit, such as the National

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<sup>213</sup> Ibid.

<sup>214</sup> Ibid, 6.

<sup>215</sup> McGovern, ACT UP Oral History Project, 20. Some of the articles explaining McGovern's protest include: Catherine Woodard, "Women Sue Over AIDS Help," *New York Newsday*, October 2, 1990, p. 1, and "'Disadvantaged' Sue Over AIDS Benefits," *USA Today*, October 2, 1990, and Josh Barbanell, "US Is Sued Over AIDS Benefits," *New York Times* October 2, 1990.

<sup>216</sup> Ibid., p. 25

<sup>217</sup> Ibid., p. 34

<sup>218</sup> Maxine Wolfe, ACT UP Oral History Project, 87.

Organization of Women the American Civil Liberties Union, and the Lambda Legal Defense Fund, brought increased funding and awareness to the problem with the CDC's definition.<sup>219</sup>

From 1988 to 1990, ACT UP provided women with a space to coalesce and experiment with their zap actions, understandings of HIV/AIDS, and larger political goals. During these years, women in the AIDS movements exchanged ideas with other women from different backgrounds. This exchange was essential in developing the relatively privileged women of ACT UP's understandings of AIDS and activism. Women who came from careers in law and health taught other members of ACT UP how the legal and health care system operated so that activists could identify and tackle the problems that prevented women with AIDS from getting care. Meanwhile, activists who had long careers in New Left movements brought experience with zap action and alliance building that was essential in creating the successful coalition of women activists in ACT UP. Artists, many of who participated in the Whitney Museum program, too joined the organization and helped spread the message through new mediums, like film. These women used media to expose poor portrayals of AIDS and bring AIDS education to new populations. Lastly, another, smaller group of women with personal experience with the disease became AIDS activists after their own exposure. These working class women knew what women with AIDS actually needed and directed ACT UP's attention to projects that would more directly help women. Women in the AIDS movement learned from each other and each other's experiences and embraced a more inclusive version of feminism that connected AIDS to racism, classism, and sexism.

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<sup>219</sup> Ibid.

This convergence and experimentation did not come without conflict. While women in ACT UP made incredible strides, like the publication of *Women, AIDS, and Activism*, as the AIDS movement grew more diverse, that diversity brought friction. As women in ACT UP pushed the group to expand beyond its original intent of “drugs into bodies,” not all members appreciated that change. This resulted in a largely gendered conflict in ACT UP, in which some of the male members resented some of the female members for trying to force the group to evolve. Additionally, some women in the group also resented the influx of lesbian feminists and felt there was a generational-gap between the women of the 1960s and 1970s women’s movements and the younger women in ACT UP who joined solely to support their male friends with AIDS. These members, comprised mostly of men and a few women, resented some of the women in ACT UP for this process. For example, Risa Denenberg explained that, “many women, including myself to some extent, were agitated about the lack of progress on women's issues.”<sup>220</sup> This feeling of stagnation, along with the trauma of staggering death tolls, as people with AIDS were dying, leaving behind broken-hearted activists who missed their friends and colleagues. Women who set out to resolve the problems of racism, lesbian-exclusion, and organizational infighting during the women’s health movement saw ACT UP and GMHC repeating those same patterns. Instead of staying with these foundational organizations, or leaving entirely like others did, some women broke away to create new groups or join already established coalitions in order to continue their work organizing around women living with AIDS.

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<sup>220</sup> Risa Denenberg and Katie Hedger, “Email with Risa Denenberg,” July 24, 2017.

#### IV. FRAGMENTATION

Individual women, each with their own motivations for advocacy, converged in the AIDS movement of the late 1980s. While the success of the movement depended upon this diversity of voices and backgrounds to create an expansive movement, it also brought conflict. A variety of conflicts contributed to ACT UP's fragmentation. Many women felt that, despite all they did to contribute to the movement, men in the AIDS movement still relegated women with AIDS to the periphery. Several of these women also felt that lesbians were still not adequately valued for their efforts. Other women grew fed up with the continuing whiteness of the AIDS movement. They believed that despite a lot of lip service to racial inclusivity, AIDS groups were still too white. Perhaps the largest and most important reason that women left ACT UP was to join or create new groups, produce art, or turn to academia in order to better advocate for women.

ACT UP was a coalition of men and women from a variety of backgrounds and special interests. That variety, which was essential to the movement's success, also brought conflict. And as loved ones succumbed to AIDS, activists experienced burnout and grief.<sup>1</sup> The women in ACT UP responded to conflict and grief in several ways. Some women, particularly those women who had careers outside of ACT UP, like lawyer Terry McGovern, returned to their professions. The women who came into ACT UP as artists like Jean Carlomusto channeled their grief into art and media as photographers, directors,

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<sup>1</sup> Deborah B. Gould argues in *Moving Politics* that ACT UP challenged the boundaries of the "political" by bringing emotions into their fight to enact political and social change through confrontational zap action. Gould also demonstrates that ACT UP challenged ideas about sexuality by embracing sex-positivity that encouraged erotic and safe sex.

writers, and producers. Another contingent of women, particularly those career activists like Marion Banzhaf, transitioned from ACT UP to other AIDS service organizations (ASOs). In each of these different paths, activists took with them the lessons they learned from ACT UP about empowerment, sexism, racism, classism, and AIDS. They also took one of ACT UP's central tenets, the idea that activists would take grief turn that to rage, which would produce action.<sup>2</sup>

So while most women did not remain regular attendees of ACT UP into the 1990s, they continued to turn their grief and rage into action in alternative ways for many years after. Terry McGovern, for example, worked at her HIV Law Project until 1999, when she took a position at Columbia University. McGovern worked with Marion Banzhaf who left ACT UP for the New Jersey Women and AIDS Network, an education network dedicated to providing women of color with AIDS information. Meanwhile, Jean Carlomusto collaborated with other video activists to create AIDS videos and documentaries about people with AIDS. In 2015, however, she directed and produced the critically acclaimed documentary on one of ACT UP's founders, *Larry Kramer in Love and Anger*. While most women left ACT UP because of grief and conflict, they still advocated for people with AIDS in their work after ACT UP. Women in ACT UP participated in a process of collective learning, conflict, and subsequent fragmentation. In a way, grief and conflict dispersed activists to a variety of new spaces, like service organizations, the arts, the media, and academia.

Alexandra Juhasz, one of the founders of the Women's Caucus, argued that because ACT UP was so male and so white, the group was incapable to enact the kind of

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<sup>2</sup> Maggenti, ACT UP Oral History Project, 45.

change that poor women of color needed.<sup>3</sup> “ACT UP is rooted in a sense of...entitlement, that most women—certainly women of color, and certainly poor women of color—don’t have,” Juhasz recalled. In fact, she argued, the AIDS movement was only possible because of that sense of entitlement. “AIDS activism happened because people who were entitled suddenly weren’t getting what they were entitled to,” Juhasz told oral historian Sarah Schulman. The reality of AIDS, however, was very different. “Most people in the world who have AIDS don’t feel entitled to anything.... [Poor people] have been taught to not be entitled.”<sup>4</sup> And while Alexandra Juhasz was not the first woman in ACT UP to make that argument, she was the first to leave the group because of it.

The women in ACT UP also debated whether the group would be best served organizing actions or direct service. Despite being a founding member of the Women’s Caucus in 1988, Juhasz wanted to “do, sort of grittier, hands on service work” outside of the largely white, male organization.<sup>5</sup> Starting with the Shea Stadium event, Alexandra Juhasz noticed a split in ACT UP between those who wanted to do service-oriented work or action-oriented work. In fact, the reason the Women’s Caucus did both the Shea Stadium event *and* the high school safer-sex education event was because of this split. “Half of the women wanted to do the Shea Stadium event,” she remembered. “And half of the women wanted to do much more direct service.”<sup>6</sup> However, this type of service work, she argued, was not “sexy” and thus did not draw the kind of attention and turnout

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<sup>3</sup> Juhasz, ACT UP Oral History Project, 51.

<sup>4</sup> Ibid., p. 51.

<sup>5</sup> Ibid., p. 27.

<sup>6</sup> Ibid., p. 26.

that other events did.<sup>7</sup> Service work was not “fun” or glamorous, and activists did not draw media attention from it.<sup>8</sup> So, Juhasz and others began to move beyond ACT UP into “service provision” work.<sup>9</sup>

After spending a year as a member of ACT UP, Juhasz turned to the Brooklyn AIDS Task Force (BATF) in 1990.<sup>10</sup> Juhasz firmly “believe[d] that if you wanted to think about women and AIDS, you needed to be thinking about poverty [and] race,” and BATF provided her with an opportunity to film poor women of color living with AIDS in order to spread awareness.<sup>11</sup> She won a grant from the city to make her film that allowed her to bring \$25,000 dollars to the Task Force to set up a support group for her subjects.<sup>12</sup> Juhasz also used the money to pay the women for their participation in the film, provide meals, and even help some women find housing.<sup>13</sup>

Through her work with BATF, Juhasz finally participated in the “grittier” service that helped women but also challenged social hierarchies.<sup>14</sup> Juhasz argued by using the “power of the camera,” she combined film and politics in a way that exposed the social hierarchy that relegated women of color at the bottom.<sup>15</sup> Reflecting on her work later, Juhasz said she combined “cultural capital [and] intellectual capital” to push her feminist, political agenda. “Feminists have always been interested in non-hierarchical relations,” she explained, and making AIDS videos allowed her to explore those relations, like class,

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<sup>7</sup> Ibid., p. 27.

<sup>8</sup> Ibid., p. 28.

<sup>9</sup> Ibid., p. 27.

<sup>10</sup> Ibid., p. 44.

<sup>11</sup> Ibid., p. 47.

<sup>12</sup> Ibid., p. 47.

<sup>13</sup> Ibid., p. 46.

<sup>14</sup> Ibid., p. 26.

<sup>15</sup> Ibid., p. 39.



HIV status, culture, and activism, through the camera.<sup>16</sup> These videos, then, served to “mobilize mass media and micro-media” in a way that had never been done before.<sup>17</sup> And underlying this desire to do service work was sadness and grief. “People got really sad,” Juhasz explained. ACT UP was “born from grief and it inspired grief,” and in the face of that overwhelming sadness, many women left ACT UP.

Alexandra Juhasz’s film of BATF, *HIV TV*, was the first of many she created with Women’s AIDS Video Enterprise (WAVE).<sup>18</sup> What started in a political interest in using affordable technology, camcorders, to “represent marginal or oppositional positions” blossomed into a video support group that created AIDS education for those disproportionately affected by HIV/AIDS, black and Latina women.<sup>19</sup> For six months, Juhasz, through WAVE, filmed women with HIV/AIDS in support groups, discussing their “economic difficulties” and life experiences with the disease.<sup>20</sup> In all, WAVE created three videotapes, one of which titled *We Care: A Video for Care Providers of People Affected by AIDS*, was distributed to nearly one thousand service organizations and screened at over one hundred community organization meetings.<sup>21</sup> Juhasz argued that WAVE empowered “economically and/or culturally disenfranchised” women through education and social support.<sup>22</sup> However, despite WAVE’s successes, Juhasz felt “self-conscious” about the implications of a white-passing woman filming women who were

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<sup>16</sup> Ibid., p. 41.

<sup>17</sup> Ibid., p. 42.

<sup>18</sup> Juhasz, ACT UP Oral History

<sup>19</sup> Alexandra Juhasz, “WAVE in the Media Environment: Camcorder Activism and the Making of HIV TV,” *Camera Obscura* 28 (January 1993): 136-137.

<sup>20</sup> Ibid., p. 138.

<sup>21</sup> Ibid., p. 139.

<sup>22</sup> Ibid., p. 140.

culturally different than herself.<sup>23</sup> In an effort to distance herself from the “colonial origins of anthropology” that her work could appear to mimic, Juhasz explained that the purpose of the WAVE project was to “alter the power relations” typically seen in anthropological work by collaboratively producing the films with her subjects.<sup>24</sup> Through her AIDS activism even outside of ACT UP, Juhasz had to deal with the racial implications of her activism.

Other women challenged the role that women played in AIDS activism. Reflecting later upon her time in ACT UP, Rebecca Cole questioned her and other women’s place within the AIDS movement. She argued that women, particularly lesbians within ACT UP, had no connection to the AIDS movement and that many of the younger members only learned about AIDS from joining the organization.<sup>25</sup> It was an “odd connection,” she argued. For men, ACT UP was a place to “radicalize themselves politically,” while the lesbians in ACT UP “had been much more political for a much longer time, radicalizing themselves about some movement that wasn’t as much about them.” Instead, lesbians used the movement to make a statement about their ability to cooperatively organize with gay men after previous years of contention between the two groups. This reflection was perhaps stirred by Cole’s feelings of neglect by the other women activists in ACT UP. While ACT UP planned their demonstration at the Food and Drug Administration, Cole’s mother was diagnosed with breast cancer. Because of her mother’s diagnosis and later death, Cole had to take time away from the group. “I had to go home and take care of my mother, who had no, there was no hospice. I was hospice,”

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<sup>23</sup> Ibid.

<sup>24</sup> Ibid., p. 141.

<sup>25</sup> Cole, ACT UP Oral History Project, 55.

Cole explained, “and my friends were too busy planning the FDA action in 1988.”<sup>26</sup> Thus, Cole felt “really angry at” many of her fellow women activists.<sup>27</sup> After her mother’s death in the winter of 1988, Cole did not return to ACT UP. She argued that this incident demonstrated to her that the women in ACT UP had lost site of “the” cause and turned it into “their cause.”<sup>28</sup> Rebecca Cole, however, was not the only female AIDS activist to make this argument.

Other women also resented the way that some of the women in ACT UP transformed the organization. Garance Franke-Ruta, who had joined the organization after the FDA demonstration in 1988, did so because of ACT UP’s original purpose to get drugs into bodies. She joined the Treatment and Data Committee (T&D), the purpose of which was to “democratize health care” as people with AIDS fought for more treatment options.<sup>29</sup> T&D advocated for compassionate use—prescribing experimental drugs for people dying from AIDS—and connected people with AIDS with potential treatments.<sup>30</sup> Because of this focus, Franke-Ruta worked primarily with men in the organization. Thus, Maxine Wolfe turned her ire to Franke-Ruta. “She was awful to me,” she recalled. “She

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<sup>26</sup> Ibid., p. 48

<sup>27</sup> Ibid.

<sup>28</sup> Ibid. Lesbian activists have long been accused of transforming movements to better advocate for their needs. For example, Ruth Rosen argues in *The World Split Open* (Penguin Books, 2000) that there was a “gay-straight split” in almost all of the women’s liberation groups. Rosen demonstrates that straight women resented this, decrying that lesbians had taken over feminism, resulting in heterosexual women needing to “come out” as straight in their advocacy. Lesbian-feminists, meanwhile, argued that they were the “vanguard of the resistance,” as lesbians seemed to better embody the idea of merging the personal and political. This conflict, Rosen argues, resulted in a fragmentation and hierarchy between straight and lesbian women.

<sup>29</sup> Jennifer Brier, *Infectious Ideas*, p. 168.

<sup>30</sup> Franke-Ruta, ACT UP Oral History Project, 15. See also Brier, *Infectious Ideas*, 162.

was very mean to me.”<sup>31</sup> And because Wolfe had considerable influence as one of the leaders of the Women’s Action Committee and Women’s Caucus, many of the women in ACT UP also targeted Franke-Ruta. “They always accused me of being male-identified... which is, like, a total ‘70s feminist thing to say.”<sup>32</sup> In the face of such opposition, Franke-Ruta remained dedicated to the Treatment and Data Committee.

Some members of T&D had a fundamentally different understanding of ACT UP’s purpose than other members of the organization at large. All agreed that ACT UP’s original purpose was to put “drugs into bodies” by increasing funding for AIDS treatments.<sup>33</sup> However, some activists, particularly the lesbians and men of color in ACT UP, believed that this original platform should be expanded or revised. Catherine Saalfeld and Ray Navarro argued in 1991 that as activists learned about the kinds of institutional discrimination women of all races and men of color with AIDS faced when attempting to access education and treatment, ACT UP had a duty to dismantle those larger issues of sexism, racism, homophobia, and classism.<sup>34</sup> They argued that AIDS had a number of contributing “cofactors” that ACT UP had to address to enact real, lasting change for people with AIDS.<sup>35</sup> Jennifer Brier shows that founding members of T&D wholeheartedly objected. Peter Staley accused some in ACT UP of joining the group not as a “matter of survival,” but as a means to “seek a power base from which their social

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<sup>31</sup> Ibid., p. 48. One factor in Wolfe and Ruta’s conflict could stem from their considerable class differences. Ruta was a young, Jewish, previously homeless, high school dropout, whereas Wolfe was a white, class-privileged academic.

<sup>32</sup> Ibid.

<sup>33</sup> Catherine Saalfeld and Ray Navarro, “Shocking Pink Praxis: Race and Gender on the ACT UP Frontlines,” 351.

<sup>34</sup> Ibid.

<sup>35</sup> Ibid., p. 352.

activism could be advanced.”<sup>36</sup> Staley believed that some of ACT UP’s members prioritized fighting the racism and sexism that prevented people with AIDS from accessing treatment over advocating for the availability of AIDS treatment.

Meanwhile, members of the Women’s Caucus argued that the root of the conflict with some of the members of T&D were the relationships they had developed with people in the “AIDS industry.” As Jennifer Brier argues, both the Women’s Caucus and T&D used similar tactics when challenging the federal government, but the members of the Women’s Caucus related their battles to longer historical fights against a sexist medical industry.<sup>37</sup> Some women, like Maria Maggenti believed that T&D saw themselves more like contentious allies to the government than oppositional forces and accused them of collaborating with federal agencies like the NIH, fundamentally changing the organization. By 1990, Maggenti argued, the “AIDS industry” had developed and “people [in ACT UP] were able to make careers out of it... That changed things.”<sup>38</sup> Meanwhile Maxine Wolfe recalled that some members of T&D “actually believ[ed] that they were doing something to help people, when they were actually being pawns.”<sup>39</sup> According to Maxine Wolfe, T&D’s dedication had always been in “pushing drug stuff,” rather than focusing on women with HIV/AIDS. While Wolfe argued that this faction was not the “majority of men in ACT UP,” many of the members of the Treatment and Data Committee “actually believed that anything we did about women

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<sup>36</sup> Jennifer Brier, *Infectious Ideas*, p. 182.

<sup>37</sup> Ibid., p. 175.

<sup>38</sup> Maggenti, ACT UP Oral History Project, 44.

<sup>39</sup> Wolfe, ACT UP Oral History Project, 93.

took away from them.”<sup>40</sup> This tension between some of the male members of ACT UP and the women in the group, with the exception of Franke-Ruta, came to a head again over a drug trial in which AZT was administered to pregnant women.<sup>41</sup>

The trial, AIDS Clinical Trial Group (ACTG) 076, studied the effectiveness of AZT in preventing pregnant mothers from transmitting HIV to their unborn fetuses.<sup>42</sup> As Jennifer Brier tells it, T&D member David Kirschenbaum found it problematic that part of the study would take place in New Jersey, which had the highest number of women with HIV. Trial 076 would thus rely on a large number of women of color for their experimentation. This, combined with the fact that trial operators would not inform women with HIV that having a cesarean section would reduce their chances of passing along the virus, felt to Kirschenbaum like ACTG 076 was experimenting on women of color without informed consent.<sup>43</sup> While Jennifer Brier points to Wolfe’s rejection of the trial because it centered on “saving babies,” women in ACT UP also objected to trial 076 because any of the women in trial 076 were poor women of color.<sup>44</sup> This was troublesome, argued Marion Banzhaf, considering “the history of experimentation on

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<sup>40</sup> Wolfe, ACT UP Oral History Project, 96.

<sup>41</sup> In *Infectious Ideas*, Jennifer Brier explains that the purpose of ACTG 076 was to test the efficacy of AZT in limiting the spread of HIV from pregnant women to their unborn fetuses. Some of ACT UP’s members, including T&D member David Kirschenbaum, believed that the trial withheld important information from the female participants because it did not inform women that having a vaginal birth increased their risk of passing the virus on to their children. The trial, Kirshenbaum told ACT UP members, also gave half of the participants a placebo. As a result, some of the women in ACT UP objected, pitting themselves against the members of T&D, the Majority Actions Committee, and some of the Women’s Caucus.

<sup>42</sup> Brier, *Infectious Ideas*, p. 180.

<sup>43</sup> Ibid.

<sup>44</sup> Ibid.

black people in this country.”<sup>45</sup> While the trial was designed to see if AZT could keep women with AIDS from transmitting the disease onto their children, it brought up “larger, broader sort of medical issues beyond pumping these women full of drugs,” remembered Heidi Dorow.<sup>46</sup> In response, Maxine Wolfe argued that ACT UP had to stop the trial, while Marion Banzhaf argued that the trial should be reformatted.<sup>47</sup>

Marion Banzhaf, who had more practical experience in medicine from her time at the pro-abortion collective in Florida, knew that the trial would continue regardless of ACT UP’s protests. The trial organizers had “powerful connection. They had the funding all lined up” and would persevere “regardless of what ACT UP did.”<sup>48</sup> In addition, the trial gained support from black women, like Janet Mitchell, a doctor from Harlem who argued that the trial would be a “really good thing for pregnant women.”<sup>49</sup> So, while ACT UP conducted a zap action against 076 for its racism at a meeting in Washington D.C., essentially protesting their own organization, Dr. Mitchell supported the trial and encouraged women to sign up.<sup>50</sup> The result, recalled Banzhaf, was that ACT UP’s actions against 076 “wound up being racist. Because here was this group of largely people of color; and [ACT UP] didn’t let them hear the information and make up their minds for

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<sup>45</sup> Banzhaf, ACT UP Oral History Project, 57. Marion Banzhaf and ACT UP’s women activists would have been very familiar with Evelyn Hammonds’ 1987 article explaining the links between AIDS and the Tuskegee trials.

<sup>46</sup> Dorow, ACT UP Oral History Project, 55.

<sup>47</sup> Banzhaf, ACT UP Oral History Project, 59.

<sup>48</sup> Banzhaf, ACT UP Oral History Project, 59.

<sup>49</sup> Ibid., p. 58.

<sup>50</sup> As Brier points out in *Infectious Ideas*, white women like Maxine Wolfe and Heidi Dorow faced off against the multiracial coalition of trial 076 supporters from inside and outside of ACT UP. Brier demonstrates that the 076 debate exposed many fault lines within ACT UP and showed that the primarily-white ACT UP struggled in their efforts to advocate for people of color.

themselves.”<sup>51</sup> Banzhaf, who considered herself more “collaborative and pragmatic,” understood that some of ACT UP’s members’ demands to stop trial 076 altogether was short-sided.<sup>52</sup> However, for many of the women in the group, trial 076 was problematic which further severed the ties between some women and ACT UP.

The confrontation over trial 076 was bad enough that it was Marion Banzhaf’s last protest with ACT UP and she instead dedicated her full time to AIDS service and education. By 1990, the “AIDS landscape” had changed, Banzhaf remembered, as the government began to take the steps that ACT UP demanded. Because the group had “won some of [its] demands,” people in ACT UP started to branch out into new spaces.<sup>53</sup> Activists, including Banzhaf, turned then to AIDS service organizations in order to build coalitions with other people with AIDS.<sup>54</sup> Banzhaf began to work at the New Jersey Women and AIDS Network (WAN), a group started by “feminists who were working in prisons, who were working in Planned Parenthood, and who were working in rape crisis centers and domestic violence shelters.”<sup>55</sup> WAN’s mission was to educate other AIDS groups about how the disease manifested in women because “AIDS groups didn’t know anything about women.”<sup>56</sup> Focused in New Jersey, the state with “the highest proportion of women with AIDS in the country,” Banzhaf steered WAN to focus primarily on women of color.<sup>57</sup>

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<sup>51</sup> Ibid., p. 61.

<sup>52</sup> Ibid.

<sup>53</sup> Ibid., p. 64.

<sup>54</sup> Ibid.

<sup>55</sup> Ibid., p. 69

<sup>56</sup> Ibid.

<sup>57</sup> Ibid., p. 58.



According to Marion Banzhaf, WAN was the “first, statewide women-and-AIDS organization in the country.”<sup>58</sup> Focusing on “education and advocacy,” WAN’s goal was to “educate healthcare providers, government officials, and the general public about the particular problem of women with AIDS.”<sup>59</sup> Part of this education consisted of teaching doctors about the unique problems women with AIDS faced. WAN member Ellen Kotten told reporters, “Gynecological problems frequently are the first symptoms... this information is not known by many physicians.”<sup>60</sup> WAN operated as a grassroots, community-based collective of seventy-five female AIDS activists from a variety of different activist and advocacy organizations. Focused around the issue of teaching women, doctors, and the public about AIDS, WAN grew as more diverse populations began to join the network.<sup>61</sup>

At its largest, WAN boasted over three hundred members, most of who worked primarily for city and state agencies that focused on drug treatment, family planning, and domestic violence, and thus understood the needs of poor women with AIDS. “It’s about lack of health care,” Banzhaf explained when asked about the purpose of her network. WAN would only come to end, she said, when “healthcare policies deal honestly and humanely with women.”<sup>62</sup> WAN members recognized the unique problems AIDS presented to women of color. “I think that if 78% of women with AIDS were white and middle class that the government would have made fighting this disease a higher

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<sup>58</sup> Carole G. Rogers, “A Group’s Concern: Women and AIDS,” *New York Times*, December 29, 1991, sec NJ3.

<sup>59</sup> Ibid.

<sup>60</sup> Louise Saul, “AIDS and Its Toll on Women,” *New York Times*, September 17, 1989, sec. NJ3.

<sup>61</sup> Ibid.

<sup>62</sup> Ibid.

priority,” Banzhaf told a reporter.<sup>63</sup> And to keep the needs of women of color living with AIDS in focus, Banzhaf purposefully recruited women of color to serve on the steering committee, so that nearly half of the board was made up of black and Latinx women, finally accomplishing what the women of ACT UP had desired to do.<sup>64</sup> Through her work with WAN, Banzhaf created a network of resource for education and treatment for women, particularly women of color, with AIDS.

Marion Banzhaf also allied with Terry McGovern during their negotiations with the CDC after leaving ACT UP. Despite her legal victory against the SSA, McGovern struggled to force the CDC to also update its definition and thus continued to work alongside activists to keep the pressure on the agency. In one campaign, Heidi Dorow and the Women’s Caucus targeted the head of the CDC’s HIV/AIDS Division, James Curran, by printing 10,000 postcards with an image of Curran with an archery target on his face.<sup>65</sup> Dorow distributed these postcards to social workers, health care workers, activists, people living with AIDS, and other AIDS organizations and she encouraged them to mail the cards to Curran with their thoughts on the CDC policy. Shortly after the postcard campaign, Dorow learned that Curran would be visiting the CDC’s New York City office. The Women’s Caucus unfurled a banner outside the building facing Curran’s office that was “huge, long, three to five stories high, ginormous,” and read, “CDC Kills.”<sup>66</sup> Dorow sought to “beat them until they yield” to activist demands to update the

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<sup>63</sup> Ibid.

<sup>64</sup> Ibid.

<sup>65</sup> Dorow, ACT UP Oral History Project, 48.

<sup>66</sup> Ibid., 50.

CDC's definition in order to "increase benefits to poor women."<sup>67</sup> Dorow confronted the CDC for its misinformation and subsequent mistreatment of women with AIDS in order to shame the agency and force a correction.

Through the Women's Caucus, ACT UP supplied money for busses and organized demonstrations that greatly helped McGovern's case, but this partnership was not always an easy one, as ACT UP members did not always understand the legal specifics that McGovern did. For example, Wolfe and ACT UP wanted many additions made to the CDC's AIDS definition, but McGovern understood that only diseases that had overwhelming medical evidence connecting it to AIDS could be included in the definition. "I was always looking for what was legally provable," McGovern recalled. "And the activists were looked for what *should* be there."<sup>68</sup> And when McGovern learned that members of ACT UP's T&D Committee had "high-level meetings" with the CDC and SSA with her, she grew "incensed."<sup>69</sup> McGovern felt excluded from her own process, and more importantly, felt that activists inhibited progress for her clients. While in the negotiation process, for example, Katrina Haslip died before ever receiving an AIDS diagnosis or her rightful benefits.<sup>70</sup> Her clients with AIDS, for example, felt that including a T-cell count in the AIDS definition was incredibly important. Meanwhile, activists were more concerned with adding pelvic inflammatory disease to the definition.

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<sup>67</sup> Ibid., 51.

<sup>68</sup> McGovern, ACT UP Oral History Project, p. 35.

<sup>69</sup> McGovern, ACT UP Oral History Project, p. 31.

<sup>70</sup> McGovern, ACT UP Oral History Project, p. 35.

So, when activists suggested that due to lack of progress, they “should not compromise at all” and thus “bag” the negotiations with the CDC, McGovern balked.<sup>71</sup>

Some activists, like Heidi Dorow and Maxine Wolfe, felt that accepting compromise would be counterproductive. “In my mind,” Dorow recalled, “the campaign was about fight until we win; we don’t negotiate until we win.”<sup>72</sup> Activists were playing “hardball” and only “zap action wins this ball game,” Dorow argued.<sup>73</sup> Maxine Wolfe felt similarly, and believed that ACT UP had enough political power to have all of their demands met. “They were so afraid of us by that time,” she explained. “We had done all these demonstrations. We had gotten groups that were so diverse to support this campaign from all over the country... It went from the grass roots up.”<sup>74</sup> With the power that the group had, several women in ACT UP believed that if they held out long enough, the CDC would bend to their demands.

While ACT UP spent considerable time and money working towards changing the CDC definition, Garance Franke-Ruta “couldn’t take it anymore” and left ACT UP in 1991 to form an activist group focused specifically fighting for treatment called Treatment Action Group (TAG).<sup>75</sup> The point of action, argued Franke-Ruta, was to work towards a specific goal, and ACT UP was no longer doing that. Instead, members of ACT UP organized protests without goals, which was “an extremely inefficient strategy of creating change.” Therefore, some ACT UP members argued that the Treatment and Data

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<sup>71</sup> Ibid.

<sup>72</sup> Dorow, ACT UP Oral History Project, 53.

<sup>73</sup> Ibid.

<sup>74</sup> Wolfe, ACT UP Oral History Project, 91.

<sup>75</sup> Franke-Ruta, ACT UP Oral History Project, 49. Ruta clarifies that TAG was short for both Treatment Activist Guerillas and Treatment Activist Group, depending upon the context.

Committee was reactive, rather than proactive.<sup>76</sup> TAG, however, was a more “proactive... think tank as well as activist group” that would center on projects and applying for research grants rather than protest.<sup>77</sup> While TAG members promised in ACT UP newsletters that the move was not a split between activists and ACT UP, the leading members of the Treatment and Data Committee stepped down from their positions of leadership in ACT UP for TAG. Thus, regardless of TAG’s intent, its creation fractured ACT UP.

This resentment came to a head over Garance Franke-Ruta’s invitation to ACT UP to contribute to a women’s version of GMHC’s usual publication, *Treatment Issues* in 1992. GMHC had been publishing *Treatment Issues* since its formation in the early 1980s, but the editors had yet to dedicate an issue to women living with AIDS. In a letter of refusal, the CDC Working Group’s William “Bro” Broberg and Dorow wrote that they had to “draw a line when it comes to publishing with GMHC.”<sup>78</sup> Expressing dismay that GMHC had not participated in several ACT UP protests in the previous year, the Working Group did not approve of GMHC’s “inability and seeming unwillingness to effectively push leftward the center.”<sup>79</sup> They charged them with a conservatism that was ushered in through increased professionalization. ACT UP already disapproved of

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<sup>76</sup> Committees, Treatment and Data Digest, 1992. 1992. MS ACT UP: The AIDS Coalition to Unleash Power: Series VII. Committees Box 62, Folder 4. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5qPMc6>. Accessed 25 Jan. 2018.

<sup>77</sup> Ibid.

<sup>78</sup> Published and near Print Material, Media (1 of 3), January 13-February 25, 1992. January 13-February 25, 1992. MS ACT UP: The AIDS Coalition to Unleash Power: Series X. Published and near Print Material Box 144, Folder 12. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tNMb5>. Accessed 23 June 2018.

<sup>79</sup> Ibid, 2.

GMHC's participation with the medical establishment, but their refusal to protest outside of the CDC was the last straw for the Working Group. "It is a great disappointment," Dorow continued, "that you do not use your unique position to yield greater results."<sup>80</sup> Despite acknowledging that GMHC was not primarily a political organization, Dorow pressured the organization to "step out of line." ACT UP's CDC Working Group expressed clear annoyance with GMHC's increasingly professionalized role in the crisis.

Dorow and ACT UP's frustration was not one-sided. In her response on behalf of GMHC's *Women's Treatment Issues*, editor Garance Franke-Ruta bitinglly hoped that the Working Group would "find a less politically objectionable [forum] for reaching the 50,000 people" who would read the issue.<sup>81</sup> Franke-Ruta pointed out the flaw in ACT UP's response: the goal of both the Working Group and GMHC was to "get information to women living with HIV and their care providers." Not contributing an article would fly in the face of both group's goals. Further, Franke-Ruta lambasted the "us/you" dynamic in the Working Group's letter. Since the beginning of both groups, members have participated in both organizations, including Garance Franke-Ruta. "As an ACT/UP AIDS activist arrested at the CDC Demonstration in 1990," the Working Group's letter was "odd" and divisive for Franke-Ruta.<sup>82</sup>

Heidi Dorow took on GMHC again when the CDC Working Group protested the CDC's lack of response to growing scientific evidence of HIV/AIDS infections in

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<sup>80</sup> Ibid.

<sup>81</sup> Published and near Print Material, Media (1 of 3), January 13-February 25, 1992. January 13-February 25, 1992. MS ACT UP: The AIDS Coalition to Unleash Power: Series X. Published and near Print Material Box 144, Folder 12. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tNMb5>. Accessed 23 June 2018.

<sup>82</sup> Ibid, 2.

women. At a 1992 meeting with the CDC and national AIDS organizations, including GMHC, ACT UP members burst into the meeting room to conduct a sit-in. Dorow explained that the group “viewed this essentially secret meeting as perhaps the last chance to confront the CDC on its proposed changes to the AIDS definition.”<sup>83</sup> ACT UP protestors brought in handcuffs and attached themselves to the invited members of the meeting. ACT UP members refused to leave until the CDC took some action or the attending members of AIDS organizations supported ACT UP’s stance. The attendees did not bend to the activists; instead one attendee, a member of GMHC, called the protest an “act of violence committed against our own community.”<sup>84</sup> This served as Heidi Dorow’s last action with ACT UP, as the tension within ACT UP grew too much for her.<sup>85</sup> She stopped attending meetings and turned to anti-poverty advocacy, becoming the director of the Urban Justice Center’s Organizing Project.<sup>86</sup>

For Marion Banzhaf, this action demonstrated that ACT UP no longer saw AIDS service organizations as allies, but as enemies. These service organizations, like her Women and AIDS Network, instead became “the monster, the AIDS industrial complex.”<sup>87</sup> These “skirmishes” between AIDS service organizations, like GMHC, and ACT UP, were perhaps fueled by the immense grief felt by those who lost loved ones to HIV/AIDS. Many AIDS activists felt that they had to keep planning, keep organizing,

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<sup>83</sup> Heidi Dorow, “Sold Down the River: Women with HIV, the AIDS Mafia and the CDC Definition,” *New York Quarterly*, March 1, 1992, 44.

<sup>84</sup> Nick Bartolomeo, “ACT UP Action Called ‘Act of Violence’ Against Community,” *Washington Blade*, February 28, 1992.

<sup>85</sup> Heidi Dorow, ACT UP Oral History Project, 65.

<sup>86</sup> Heidi Dorow and Peter Laarman, “Letter to the Editor: Workfare’s Darker Side,” *New York Times*, July 28, 1997, sec. A16.

<sup>87</sup> Banzhaf, ACT UP Oral History Project, 76.

and keep acting in order to save peoples' lives. For example, Maria Maggenti explained that "the prevailing attitude in the group... was that you would take your grief and you would turn it into rage, and you would take that rage and you would do something with it."<sup>88</sup> As historian Deborah Gould demonstrated, that anger proved as a tool to unite a fragile coalition of activists.<sup>89</sup> However, by channeling their grief into action, members put off their feelings of sadness. In fact, Maggenti remembered mocking the idea of stages of grief in favor of developing a personal "toughness" instead.<sup>90</sup> Despite their best efforts, this "cumulative effect of grief," as explained by Jean Carlomusto, was traumatic.<sup>91</sup> This trauma would continue to push women away from ACT UP in favor of other methods of AIDS activism.

Like many of the women who transitioned from ACT UP to other groups, Karen Ramspacher felt that she "kind of just moved tactics," when she left the activist group for work in health education.<sup>92</sup> Ramspacher first worked as the director of the Women's Health Project at Community Health Project (CHP). CHP, a community based health clinic, originally did not have the space for women with HIV. In 1990, however, it became clear to the project founders that women with AIDS represented a growing population who needed care. Thus, to "ensure effective recognition and management of gynecologic disease in the increasing number of women attending our clinic," CHP

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<sup>88</sup> Maggenti, ACT UP Oral History Project, 45.

<sup>89</sup> Gould, *Moving Politics*, 304.

<sup>90</sup> Maggenti, ACT UP Oral History Project, 1.

<sup>91</sup> Carlomusto, ACT UP Oral History Project, 10.

<sup>92</sup> Ramspacher, ACT UP Oral History Project, 41.



created the Women's Health Project.<sup>93</sup> However, perhaps learning about lesbian visibility from the women in ACT UP, Ramspacher left the position shortly after beginning because it was clear to her that a lesbian should be in that position. Ramspacher explained, "In truth it should have been a Lesbian Health Project, so we renamed it, and then I stepped down because I'm not a lesbian, and I thought it should be run by a lesbian."<sup>94</sup> So, Ramspacher returned to her project at ACT UP, the Youth Education Lifeline (YELL).

While working for the Community Health Project, Ramspacher took YELL, a group that started as a subcommittee in ACT UP, into a full-fledged non-profit organization. Within ACT UP, YELL fought for "students' rights to comprehensive AIDS education" that included free condoms, dental dams, and clean needles in high schools across New York City.<sup>95</sup> By 1992, the group successfully distributed safer sex information and prophylaxis to over 45,000 students.<sup>96</sup> In YELL, Ramspacher worked as a researcher, applying her "professional research skills to bring this issue [of safer sex education in schools] to the fore."<sup>97</sup> Ramspacher used the skills she learned from WHAM! and ACT UP to spread AIDS education to students, while other women took their skills and created new organizations.

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<sup>93</sup> Subjects, Women and AIDS / HIV Research (3 of 4), 1986 - 1990. 1987-1990. MS ACT UP: The AIDS Coalition to Unleash Power: Series VIII. Subjects Box 113, Folder 5. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5r67d2>. Accessed 28 Jan. 2018.

<sup>94</sup> Ramspacher, ACT UP Oral History Project, 19

<sup>95</sup> Ephemera, Flyers, Handbills by ACT UP, Yell (Youth Education Life Line). n.d. MS ACT UP: The AIDS Coalition to Unleash Power: Series XI. Ephemera, Flyers, Handbills by Act Up Box 195, Folder 17. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5r64G0>. Accessed 28 Jan. 2018.

<sup>96</sup> Ibid.

<sup>97</sup> Ramspacher, ACT UP Oral History Project, 21.

Like Ramspacher, Maxine Wolfe began to spend her time with other organizations, and while still attending ACT UP meetings, helped form the direct action group, Lesbian Avengers, with other ACT UP members.<sup>98</sup> Spurred by the election of Bill Clinton in 1992, the purpose of the Lesbian Avengers, according to *Newsweek* journalist Eloise Salholz, was to “cast off their role as handmaidens to other activists and stake their own claims.”<sup>99</sup> Lesbian activists, Salholz, continued had long been central to the struggle against AIDS and for abortion, while the Lesbian Avengers, as remembered by founder Sarah Schulman one year later, focused solely on “issues vital to lesbian survival and visibility.”<sup>100</sup> Like ACT UP, the Lesbian Avengers ran democratic style meetings in which anyone could bring a proposal to the floor.<sup>101</sup> However, they differed fundamentally in their belief that “Chanting and picketing no longer make an impression.” Instead of “standing passively” and listening to speakers, which the Avengers considered disempowering, they argued in favor of more dramatic actions, like encampments, street art, and zaps in public and private buildings.<sup>102</sup> For protests and demonstrations, Schulman explained, Lesbian Avengers would not inform the police or apply for a permit. These tactics, many of which mirror the activities that these lesbian activists organized during the 1970s, demonstrate the frustration that some of ACT UP’s women felt over the group’s willingness to cooperate with authority figures, both the police forces and federal agencies. As part of the Lesbian Avengers, Jamie Bauer, who

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<sup>98</sup> Wolfe founded Lesbian Avengers with ACT UP’s Sarah Schulman and Anne-Christine D’Adesky.

<sup>99</sup> Eloise Salholz, “The Power and the Pride,” *Newsweek Magazine*, June 20, 1993.

<sup>100</sup> Sarah Schulman, *My American History: Lesbian and Gay Life during the Reagan/Bush Years* (New York: Routledge, 1994), 96.

<sup>101</sup> Ibid.

<sup>102</sup> Ibid.

came to ACT UP from the anti-nuclear war movement, continued to teach women how to practice nonviolent civil disobedience.<sup>103</sup> Part of Bauer, and the Avengers', larger problem with the AIDS movement was the willingness of some of ACT UP's members to work with groups like GMHC and federal agencies.<sup>104</sup>

Other of ACT UP's members, like Jean Carlomusto, argued that the relationship between GMHC and ACT UP had become "unnecessarily acrimonious" and grew tired of the conflict.<sup>105</sup> Instead of collaborating with ACT UP, Carlomusto turned to GMHC to produce her next tapes. Carlomusto enjoyed working with GMHC because of the budding feminism within the group, which was largely due the work of "poor-white-trash, working-class, high-femme dyke," Amber Hollibaugh.<sup>106</sup> Hollibaugh considered herself somewhat of a veteran in the AIDS epidemic. She began doing caretaking "AIDS work," which quickly transformed into "AIDS activism" in the first years of the crisis. Hollibaugh identified herself as one of a "large contingent of lesbians" who responded to the crisis because "the communities most under siege were exactly the communities [we] were committed to working within (women in prisons, poor women, women of color,

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<sup>103</sup> Jamie Bauer, transcript of an oral history conducted in 2017 by Michelle Esther O'Brien, New York City Trans Oral History Project (New York: New York University, 2017), <https://s3.amazonaws.com/oral-history/transcripts/NYC+TOHP+Transcript+015+Jamie+Bauer.pdf>, accessed March 22, 2018, 16.

<sup>104</sup> Ibid.

<sup>105</sup> Jean Carlomusto, ACT UP Oral History Project, 38.

<sup>106</sup> Amber Hollibaugh, transcript of an oral history conducted in 2003 by Kelly Anderson, Voices of Feminism Oral History Project (Northampton, MA: Smith College, 2004), <https://www.smith.edu/libraries/libs/ssc/vof/transcripts/Hollibaugh.pdf>, accessed 22 Aug. 2017, 37.

young women).”<sup>107</sup> Thus, Hollibaugh directed her community work towards women with AIDS.

Amber Hollibaugh felt particularly disappointed by the results of the “sex wars” of the 1980s and vowed to embrace a sex-positive type of AIDS education for women.<sup>108</sup> Hollibaugh was the keynote speaker at the 1982 Barnard Conference that ignited the “sex wars,” presenting a paper she co-wrote with Chicana activist Cherrie Moraga.<sup>109</sup> In the piece, “What We’re Rollin Around in Bed With,” Hollibaugh and Moraga argued that feminism had neglected women’s sexuality.<sup>110</sup> Hollibaugh argued that feminists had to embrace a positive understanding of sex and pleasure, rather than focusing solely on sex as a means of oppression.<sup>111</sup> Hollibaugh advocated against the “right wing drift of the sex wars” in which feminists, lesbian feminists, and anti-pornography advocates battled bitterly over the value, or disvalue, of pornography.<sup>112</sup> Hollibaugh, and many of ACT UP’s women activists, believed pornography could be a positive expression of female sexuality.<sup>113</sup> The debate, Hollibaugh later argued, showed the fault lines between the movements of women’s liberation, lesbian feminism, and gay liberation.<sup>114</sup> The sex wars made Hollibaugh “deeply disillusioned and bitter,” so she turned her attention to creating

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<sup>107</sup> Ibid., p. 220.

<sup>108</sup> Amber Hollibaugh, “Seducing Women Into ‘A Lifestyle of Vaginal Fisting: Lesbian Sex Gets Virtually Dangerous,’” in *Policing Public Sex: Queer Politics and the Future of AIDS Activism*, Dangerous Bedfellows eds., (Boston, MA: South End Press, 1996), 325.

<sup>109</sup> Hollibaugh, Voices of Feminism Oral History Project, p. 137.

<sup>110</sup> Cherrie Moraga and Amber Hollibaugh, “What We’re Rollin Around in Bed With: Sexual Silences in Feminism, A Conversation toward Ending Them,” *Heresies* 12 (Spring 1981): 58.

<sup>111</sup> Ibid.

<sup>112</sup> Hollibaugh, Voices of Feminism Oral History Project, p. 220.

<sup>113</sup> Ibid., p. 139.

<sup>114</sup> Hollibaugh, “Seducing Women Into ‘A Lifestyle of Vaginal Fisting: Lesbian Sex Gets Virtually Dangerous,’” 325.

a “new revolution, made up of lesbians, working-class women, women in prison, women of color, sex workers, women who shot drugs and women in recovery from those drugs and the street,” amongst a slew of other women at risk.<sup>115</sup> According to Hollibaugh, the AIDS crisis brought these women of varying backgrounds and experiences together.<sup>116</sup>

When she took a position as the Director of Education at the AIDS Discrimination Unit of New York City in 1983, Amber Hollibaugh fought against what she saw as a “narrowing” of the women’s movement by merging her radical sex-positive feminism with the AIDS crisis.<sup>117</sup> As an AIDS educator, Hollibaugh served a very practical purpose by traveling around New York City, distributing information about the transmission of HIV/AIDS. However, through this process, she created a community of people who felt “extremely isolated in their attempts to deal with this crisis,” she explained in 1987.<sup>118</sup> AIDS allowed Hollibaugh to bring together and empower people from disenfranchised communities, from drug users to sex workers to gay men.<sup>119</sup> Hollibaugh argued that in order for AIDS activism and advocacy to be successful, AIDS workers *had* to understand how the virus affected a variety of communities.<sup>120</sup> As a filmmaker, educator, and

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<sup>115</sup> Hollibaugh, *Voices of Feminism Oral History Project*, p. 220-221.

<sup>116</sup> Amber Hollibaugh was not alone in this sentiment. While anti-porn advocates argued that pornography was intrinsically connected to sexual violence against women, Freedman and D’Emilio demonstrate in *Intimate Matters* p. 350-352 that other feminists felt wary about the potential censorship of women’s erotic expressions that anti-porn activists seemed to advocate. Women could enjoy pornography without necessarily perpetrating violence against women or subjugation under men.

<sup>117</sup> Hollibaugh, *Voices of Feminism Oral History Project*, p. 154.

<sup>118</sup> Amber Hollibaugh et al., “The Second Epidemic,” *October* 43, no. AIDS: Cultural Analysis/Cultural Activism (Winter 1987): 130.

<sup>119</sup> *Ibid.*, p. 132.

<sup>120</sup> *Ibid.*, p. 136.

advocate Hollibaugh made a name for herself by addressing the racism, heterosexism, and classism at work in AIDS activism.

So in 1992, when the men of Gay Men's Health Crisis (GMHC) wanted to start a project for lesbians with AIDS, Amber Hollibaugh was their natural pick to lead. Hollibaugh founded the Lesbian AIDS Project (LAP) in order to create educational outreach for the "distinct and varied lesbian and female bisexual communities."<sup>121</sup> ACT UP, according to Hollibaugh, was neglecting the needs of lesbians and people of various class backgrounds in its organization. "I didn't particularly like ACT UP... I felt like they didn't deal with class and race a lot and I was working in prisons and working in foster shelter systems and working in SROs [single-room occupancy hotels] and around drug abuse...."<sup>122</sup> LAP would better address to needs of lesbians from different class positions, she argued.<sup>123</sup> LAP recognized that because lesbians were largely left out of the CDC's conception of AIDS, many women were unaware that their behaviors could expose them to AIDS. In 1993, the members of LAP distributed a leaflet describing this problem. "Lesbians' risk for AIDS has not been accounted for," Hollibaugh wrote. She explained that LAP was committed to "lesbian visibility, lesbian, bisexual, and women who sleep with other women having HIV/AIDS knowledge," along with "support for HIV+ lesbians and lesbians who have AIDS."<sup>124</sup> Despite working within a care group comprised mostly

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<sup>121</sup> Subjects, Lesbian AIDS Project (GMHC). 1990-1994. MS ACT UP: The AIDS Coalition to Unleash Power: Series VIII. Subjects Box 96, Folder 10. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/69dRN2>. Accessed 18 Mar. 2018.

<sup>122</sup> Hollibaugh, *Voices of Feminism Oral History Project*, p. 154.

<sup>123</sup> Ibid.

<sup>124</sup> Ephemera, Flyers, Handbills by ACT UP, GMHC (Gay Men's Health Crisis). February 7, 1992-March 16, 1995. MS ACT UP: The AIDS Coalition to Unleash Power:

of gay men, the Hollibaugh's work with LAP worked to protect lesbians and women who had sex with women by educating them on their risks. Dedicated to "enlarging understanding of who is affected by the epidemic and to educating about our risk for HIV among the distinct and varied lesbian and female bisexual communities to which lesbians belong,"<sup>125</sup> LAP created and distributed AIDS educational pamphlets to help women transition out of prison, and teach safe sex to "women who partner women."<sup>126</sup> Hollibaugh's use of "women who partner women" reflected her effort to reach women who did not identify as lesbians, but still had sex with other women.

Describing LAP's work as based on "community, visibility, and resource-sharing," Hollibaugh and other lesbian members of GMHC began outreach to the largely marginalized population of lesbians and women who had sex with other women living with AIDS in New York City. In order to bring new members into the Lesbian AIDS Project, members began to hold various held social events with included AIDS information for lesbians, bisexual women, and other women who had sex with women. Often held at hospitals, health clinics, or local community centers, these events invited guest speakers with varying forms of AIDS knowledge. Hollibaugh invited ACT UP's Risa Denenberg to teach lesbians safer sex practices while also explaining the barriers faced by women living with AIDS in receiving adequate medical care. She also screened

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Series XI. Ephemera, Flyers, Handbills by Act Up Box 197, Folder 2. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5tNUH1>. Accessed 22 Aug. 2017.

<sup>125</sup> Amber Hollibaugh, "Lesbian Denial and Lesbian Leadership in the AIDS Epidemic," in *Women Resisting AIDS: Feminist Strategies for Empowerment* (Philadelphia: Temple University Press, 1995): 223.

<sup>126</sup> *Ibid.*, p. 222.

Jean Carlomusto's *Current Flow* video.<sup>127</sup> The social outreach worked and the project grew from 12 to 400 women in one year, and reached 1,200 members by its third year in action. LAP merged activism and advocacy worked to educate lesbians on their risks, encourage them to incorporate safer sex practices into their sex lives, and connect them with the larger AIDS activist community.

While ACT UP activists like Jean Carlomusto helped turn GMHC from a primarily white male organization to one that centered the needs of lesbians through its Lesbian AIDS Project, she and other activists, like Maria Maggenti, Zoe Leonard, Catherine Saalfeld, and Risa Denenberg also channeled their grief through art. After “burning out” and leaving GMHC in 1994, Carlomusto has produced numerous films on AIDS, lesbian history, and abortion.<sup>128</sup> Her 1997 piece *To Catch a Glimpse*, for example, covers Carlomusto's own family history as she examined whether an illegal abortion was the cause of her grandmother's death.<sup>129</sup> The film was displayed at New York's Modern Museum of Art.<sup>130</sup> Carlomusto's most well known film, *Larry Kramer In Love & Anger*, showed at Sundance Film Festival and garnered an Emmy nomination.<sup>131</sup> The film, described New York Times columnist Mike Hale, featured how Kramer's “relentless fury and in-your-face activism” brought AIDS activism to the forefront of public

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<sup>127</sup> Published and near Print Material, Lap Notes. 1993. MS ACT UP: The AIDS Coalition to Unleash Power: Series X. Published and near Print Material Box 184, Folder 21. New York Public Library. *Archives of Sexuality & Gender*, <http://tinyurl.galegroup.com/tinyurl/5vmivX>. Accessed 11 Jan. 2018.

<sup>128</sup> Carlomusto, ACT UP Oral History Project, 41.

<sup>129</sup> Jean Carlomusto, “Films and Projects,” <https://www.jeancarlomusto.com/films-projects>. Accessed 10 Feb. 2018.

<sup>130</sup> Museum of Modern Art, “Art and Artists: Jean Carlomusto, *To Catch a Glimpse*, 1997,” <https://www.moma.org/collection/works/120258>. Accessed 10 Feb. 2018.

<sup>131</sup> Jean Carlomusto, “Films and Project.”



awareness.<sup>132</sup> However, as Hale points out, Carlomusto also made sure to portray how Kramer's polarizing "stridency, self-righteousness and bullying tactics" also created conflict in GMHC and ACT UP.<sup>133</sup> In fact, Carlomusto explained, hers was one of the few films about Kramer as he "repeatedly denied" filmmakers' attempts to document his life. "I persisted," she told an interviewer at Sundance—a skill Carlomusto said she learned from Kramer himself.<sup>134</sup> The production of the film was driven by Carlomusto's desire to investigate "subjects often left to the periphery of our culture."<sup>135</sup> Underlying her work, with *Larry Kramer In Love & Anger* and her other films, Carlomusto explained, was the need to encourage "individuals to change the world... to see the importance of standing up and fighting for what they believe in."<sup>136</sup> This goal was similar to the goal she had when creating AIDS films in the 1980s and early 1990s. Throughout her career as a director and producer, from *Testing the Limits* and *Current Flow* to *Larry Kramer In Love & Anger*, Carlomusto showcased untold stories of marginalized people, holding true to her lifelong dedication to using film to better represent people with AIDS.

Maria Maggenti had a similar goal after leaving ACT UP due to both grief and Maggenti's desire to become "a lesbian Spike Lee."<sup>137</sup> This departure was largely fueled by the deaths of her "chosen family," like one of ACT UP founder's Vito Russo. Despite

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<sup>132</sup> Mike Hale, "Portrait of the Rebel as an Impassioned Gay Political Activist," *New York Times*, June 28, 2015, sec. C1.

<sup>133</sup> Ibid.

<sup>134</sup> Becca Rose, "Sundance Women Directors: Meet Jean Carlomusto – 'Larry Kramer in Love and Anger,'" January 20, 2015, <http://www.indiewire.com/2015/01/sundance-women-directors-meet-jean-carlomusto-larry-kramer-in-love-and-anger-204968/>. Accessed 10 Feb. 2018.

<sup>135</sup> Ibid.

<sup>136</sup> Ibid.

<sup>137</sup> Maggenti, ACT UP Oral History Project, 43.

ACT UP's work, "a lot of people were dying... And I really, really believed when we started that people were going to live."<sup>138</sup> These deaths acted as a "shock" to Maggenti's system and instead of "dealing with grief," Maggenti kept herself "very, very busy."<sup>139</sup> To keep herself busy, Maggenti decided she would apply to New York University's graduate school to make films about lesbians.<sup>140</sup> Her first major film, *The Adventure of Two Girls in Love*, told the story of a white, working class young woman who falls in love with a wealthy African American young woman.<sup>141</sup> Purposefully subverting stereotypes "about black families and about class," Maggenti used the film to explore how "class and privilege influence feelings about sexuality, relationships, and one's relationship to the wider world."<sup>142</sup> Even after ACT UP, Maggenti was interested in the same issues. However, for Maggenti, the transition from activism to art severed her from the community she had built through her activism.<sup>143</sup>

Zoe Leonard, on the other hand, questioned her connection to the art world during her time as an AIDS activist. After spending time in ACT UP, she was unsure if she was "really an artist" or if she turned to art simply because her activist colleagues also did. So, in 1992, Leonard left ACT UP and New York City in favor of a few years of travel, from India to Cape Cod, and artistic development. During this year, she wrote the poem "I want a president," in which she expressed her desire to have a president with AIDS, or

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<sup>138</sup> Ibid., p. 44.

<sup>139</sup> Ibid., p. 45.

<sup>140</sup> Ibid., p. 49.

<sup>141</sup> Louis Aguilar, "Labor of Love Comes to Life," *Washington Post*, May 4, 1995, sec. MD1B.

<sup>142</sup> Maria Maggenti, Dennis West, and Joan M. West, "An Incredibly True Cinematic Adventure: An Interview with Maria Maggenti," *Cineaste* 21, no. 4 (1995): 41.

<sup>143</sup> Maggenti, ACT UP Oral History Project, 58.

with no health insurance, or had experienced sexual harassment.<sup>144</sup> In “I want a president,” Leonard lamented that “a president is always a clown: always a john and never a hooker. Always a boss and never a worker, always a liar, always a thief and never caught.”<sup>145</sup> Leonard examined the power imbalance between president and people and desires to see that imbalance rectified by electing an official with similar life experiences as marginalized people. Leonard believed that she used art to enact change, arguing that while “it’s not the same as changing a piece of legislation...the arts [are a] place where we figure out who we are and who we want to be and what’s wrong and how we want to move forward.”<sup>146</sup> So, by using her art to spark a conversation, Leonard hoped to still enact social change.

Zoe Leonard’s focus shifted from social to environmental issues after she moved to Alaska in 1994, but for her, the problems were deeply connected. In a 2002 interview, Leonard argued that the social issues she protested in New York City, like AIDS, health care, and women’s rights, paralleled issues of hunting regulations, oil, and Native American rights in Alaska.<sup>147</sup> Both problems grew from the same “beast:” capitalism.<sup>148</sup> Leonard argued that “big business is incompatible with a healthy society” in which issues like the AIDS crisis and environmental degradation and abuse flourished.<sup>149</sup> Leonard carried this theme through her art exhibition *Strange Fruit*, in which she examined “the

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<sup>144</sup> Zoe Leonard, “I Want a President,” *Women’s Studies Quarterly* 41, no. 3/4 (Fall/Winter 2013): 230.

<sup>145</sup> Ibid.

<sup>146</sup> Leonard, ACT UP Oral History Project, 64.

<sup>147</sup> Beth Dungan and Zoe Leonard, “An Interview with Zoe Leonard,” *Discourse* 24, no. 2 (Spring 2002): 76.

<sup>148</sup> Ibid.

<sup>149</sup> Ibid.

conflict between hanging on and letting go.”<sup>150</sup> Made of scraps of fruit, like bananas and apples, adorned with thread, zippers, and buttons, Leonard considered *Strange Fruit* a piece of mourning.<sup>151</sup> Through the creation of the piece by sewing together fruit rinds, Leonard felt like she was also “sew[ing] [her] self back up.”<sup>152</sup> And while not considering herself a “political artist,” Leonard allows her “worldview to seep into [her] work.”<sup>153</sup> Ultimately, her work is “steeped” in Leonard’s interest in using art to examine the power dynamics between people, and between people and nature.<sup>154</sup>

Likewise, Catherine Saalfield created films about AIDS even after leaving ACT UP. After the Stop the Church demonstration, Saalfield experienced incredible loss through the deaths of close friends and roommates Ray Navarro and Robert Garcia.<sup>155</sup> Their deaths were “overwhelming” and in response, Saalfield spent several months living in Mexico to “process” their deaths.<sup>156</sup> Upon her return to New York City, Saalfield collaborated with former ACT UP members Jean Carlomusto and Polly Thistlethwaite to create a documentary series on lesbian history called *Not Just Passing Through*. The film featured a segment on Thistlethwaite’s Lesbian Herstory Archives and examined the way that the Archives, long with Asian Lesbians of the East Coast and Wow Café,

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<sup>150</sup> Ibid., p. 83.

<sup>151</sup> Ibid.

<sup>152</sup> Anna Blume, Interview with Zoe Leonard, Paula Cooper Gallery, New York, January 18, 1997, <http://www.anthonymeierfinearts.com/attachment/en/555f2a8acfaf3429568b4568/Press/555f2b29cfaf3429568b5c35>.

<sup>153</sup> Beth Dungan and Zoe Leonard, “An Interview with Zoe Leonard,” 77.

<sup>154</sup> Ibid., 81.

<sup>155</sup> Gund, ACT UP Oral History Project, 60.

<sup>156</sup> Ibid., p. 61.

“construct[ed] lesbian-centered history, art, and politics.”<sup>157</sup> Saalfeld directed the series, which she intended for “community and classroom use” to shine a light on the ways that lesbians in the 1980s and 1990s constructed their history. And through Saalfeld’s history in AIDS activism, she met the HIV-positive performance artist Ron Athey. She featured Athey in her documentary *Hallelujah* in which she examined how “HIV status and AIDS issues manifested through [Athey’s] artwork.”<sup>158</sup> In this way, Saalfeld channeled her grief into creating art to showcase how AIDS manifested in peoples’ lives.

For other activists, the combination of painful losses and the dismissive attitude of some of ACT UP’s male members led them away from activism altogether. Risa Denenberg left the group in pursuit of an advanced nursing degree, but despite leaving ACT UP, Denenberg remained dedicated to helping women with AIDS. She continued her AIDS work through her nursing at St. Vincent’s and Bronx Lebanon Hospitals while she volunteered at the Bronx Lebanon free clinic that provided poor, often immigrant women with AIDS care. “Most of my Bronx patients were partners of IVDUs, some were drug addicts,” she recalled. “[They] were women who spoke mostly Spanish, had children, didn’t work outside the home and were very isolated from information and services.”<sup>159</sup> Through nursing, Denenberg turned away from activism, but did not leave

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<sup>157</sup> Polly Thistlethwaite, Jean Carlomusto, Catherine Gund, and Dolores Pérez, “Not Just Passing Through”, 1994. *CUNY Academic Works*.

[https://academicworks.cuny.edu/gc\\_pubs/188](https://academicworks.cuny.edu/gc_pubs/188). In *Lady Dicks and Lesbian Brothers: Staging the Unimaginable at the WOW Café Theatre*, Kate Davy chronicles the multiracial women of the Women’s One World (WOW) theater group who performed collaborative productions about women’s experiences as lesbians, as women of color, and as feminists from 1982-1985.

<sup>158</sup> Gund, ACT UP Oral History Project, 62.

<sup>159</sup> Risa Denenberg and Katie Hedger, “Correspondence with Risa Denenberg,” July 24, 2017.

AIDS work. She recalled routinely submitted letters to editors, articles, and book chapters in order to advocate for a better understanding of AIDS in women and effective AIDS services for women.<sup>160</sup> One of Denenberg's books, *Gynecological Care Manual for HIV Positive Women*, was published in 1993, and described a number of common menstrual problems women with HIV/AIDS experienced for care providers.<sup>161</sup>

In the late 1990s, Risa Denenberg transitioned from AIDS care to become a palliative care nurse, but she also turned to poetry to work through her grief.<sup>162</sup> She explained that “we were losing members weekly to AIDS deaths” and after her best friend died of AIDS-related infections in 1993, she grew tired of feeling “weary and grieving all the time.”<sup>163</sup> In her poetry, Denenberg's grief is clear. In her work, “In My Exam Room,” she describes the pain she felt as a medical practitioner helping dying patients. She wrote, “With stethoscope, I hear ruined lungs that creak like brittle timber. I palpate broken shoulders, swollen hands, marks of lumbar damage. My own pain trickles like pitch from a rift in my heart.”<sup>164</sup> And in her poem, “Pain,” Denenberg explains the feeling of “devastation” she felt seeing patients slowly succumb to illness and thus “collect[ing] reams of” pain, “tied in bundles, squirreled away in the basement.”<sup>165</sup> The pain followed her and Denenberg lamented, “No matter how close you slide towards

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<sup>160</sup> Risa Denenberg and Katie Hedger, “Correspondence with Risa Denenberg,” July 24, 2017.

<sup>161</sup> Risa Denenberg, *Gynecological Care Manual for HIV Positive Women* (Durant, OK: EMIS, Essential Medical Information Systems, 1993).

<sup>162</sup> Denenberg, ACT UP Oral History Project, 73.

<sup>163</sup> Risa Denenberg and Katie Hedger, “Correspondence with Risa Denenberg,” July 24, 2017.

<sup>164</sup> Risa Denenberg, *In My Exam Room* (Gwynedd Valley, PA: The Lives You Touch Publications, 2014).

<sup>165</sup> Risa Denenberg, *What We Owe Each Other* (Gwynedd Valley, PA: The Lives You Touch Publications, 2011).

comfort, it lurks.”<sup>166</sup> Poetry provided Denenberg with the change to work through the grief of losing loved ones and patients she knew in her career as a nurse.

Meanwhile, Polly Thistlethwaite returned to her full-time career and worked as a librarian at the Herstory Archives (LHA). “It seemed to me like a lot of the work my former colleagues doing was really focused on certain issues... [they were] full-time activists devoted to a particular set of issues, so I wasn’t as connected.”<sup>167</sup> She stopped attending meetings regularly, but Thistlethwaite continued to supply ACT UP with bibliographies. She also expanded the Herstory Archives to include the work of ACT UP and fought for increased access of uncensored archival evidence available for the public. Even at the archives, Thistlethwaite was dedicated to empowering people through access to education. She felt passionate about “working with people who needed certain kinds of medical or legal information [and] getting them into the library.”<sup>168</sup> Thistlethwaite wanted “normal” people, people off the streets who needed information, to be able to access libraries and their many resources:

When I was working at the Lesbian Herstory Archives, I was kind of building this sensibility and this critique about how archives are constructed and who gets to be in the archive and what parts of the archive are legal or extra legal or what parts are going to be available to the public, what parts are going to be excised completely. There was some evidence of personal collections being heavily edited by the New York Public Library to exclude the lesbian and the queer content in the collections.<sup>169</sup>

The belief that knowledge could empower people was a tenet of ACT UP that Thistlethwaite held long after her political activism. She took a position at CUNY

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<sup>166</sup> Ibid.

<sup>167</sup> Thistlethwaite, ACT UP Oral History Project, 49.

<sup>168</sup> Ibid.

<sup>169</sup> Ibid., p. 44.

Graduate School at the head librarian and enacted policies of “radical archiving” to bring access to archival sources to laypeople.

For Polly Thistlethwaite, radical archiving stayed true to the Lesbian Herstory Archives purpose. According to founder Joan Nestle, “the roots of the Archives lie in the silenced voices, the love letters destroyed, the pronouns changed... the euphemized distortions that patriarchy would let pass.”<sup>170</sup> Because, Thistlethwaite argued, archivists in “women’s” archives ignored lesbians because of oppression, homophobia, and sexism, the LHA established an archive to catalogue lesbian lives.<sup>171</sup> The “radical” element of the Archives came through its open access to lesbians. Women without credentials and of any race or class must still be able to enter and use the Archives, argued LHA founders, Joan Nestle and Deb Edel.<sup>172</sup> The Archive did not function like a “regular” archive in this way, but did serve a higher purpose of “creating and nourishing lesbian culture.”<sup>173</sup> And through her work as a librarian at the Archives, Thistlethwaite worked to “build a critique” of libraries and participated in “this open-access movement” in which people outside of academia could access libraries.<sup>174</sup>

Other activists too turned to academia after their work in AIDS. After spending time filming the Brooklyn AIDS Task Force, Alexandra Juhasz earned her PhD in Cinema Studies under the mentorship of Faye Ginsburg and took a position as an adjunct

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<sup>170</sup> Polly Thistlethwaite, “The Lesbian Herstory Archives,” in *Gay and Lesbian Library Service* (New York, NY: McFarland, 1991), 61.

<sup>171</sup> Ibid., p. 62.

<sup>172</sup> Ibid.

<sup>173</sup> Ibid., p. 63.

<sup>174</sup> Thistlethwaite, ACT UP Oral History Project, 45.



instructor at NYU.<sup>175</sup> It was through teaching that Juhasz found her calling, explaining that teaching, “unlike the Law, was ethical, social, and even political in ways that I could live a life by.”<sup>176</sup> While teaching at NYU and later in Philadelphia at Swarthmore College, Juhasz began writing her first book, *AIDS TV: Identity, Community and Alternative Video*, which was published in 1996. In *AIDS TV*, Juhasz examines how AIDS activists used video to “challenge traditional understandings of the media” and thus created a wave of “alternative” media.<sup>177</sup> As historian Jih-Fei Cheng argues, this “alternative” media worked to not just “visually represent” people of color, but centers entirely on the “vulnerable.”<sup>178</sup> Activists used this alternative media to showcase stories the “mainstream media” often ignored.<sup>179</sup> Thus, Juhasz argued, activists also challenged how the media represented people with AIDS.

In mainstream portrayals of people with AIDS, from NBC, CBS, and PBS, Alexandra Juhasz demonstrated that journalists portrayed women as a “contained threat,” potentially deadly through the transmission of AIDS, but also potentially contained through a return to traditional gender roles.<sup>180</sup> The mainstream media, Juhasz argued, was stuck between portraying women with AIDS as deviant vectors of disease while also trying to “perpetuate the myth that the middle-class, white male spectator” was not at

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<sup>175</sup> Laureano Ralon, Interview with Alexandra Juhasz, website, February 11, 2013, <http://figureground.org/interview-with-alexandra-juhasz>. Accessed 15 Jan. 2018.

<sup>176</sup> Ibid.

<sup>177</sup> Alexandra Juhasz and Catherine Gund, *AIDS TV: Identity, Community, and Alternative Video*, Console-Ing Passions (Durham, N.C: Duke University Press, 1995), 1.

<sup>178</sup> Jonathon Bell et al., “Interchange: HIV/AIDS and U.S. History,” *The Journal of American History* 104, no. 2 (September 2017): 452.

<sup>179</sup> Alexandra Juhasz, “So Many Alternatives: The Alternative AIDS Video Movement,” *Cinéaste* 20, no. 4 (1994): 32.

<sup>180</sup> Alexandra Juhasz, “The Contained Threat: Women in Mainstream AIDS Documentary,” *The Journal of Sex Research* 27, no. 1 (1990): 27.

risk.<sup>181</sup> To resolve this, journalists painted women as either deserving victims of AIDS whose behavior made them vulnerable to the disease or as helpless, “innocent” victims who contracted the disease through no fault of their own, like blood transfusions.<sup>182</sup> The distinction between the two, Juhasz wrote, “were, not surprisingly, drawn along lines of sexuality and concomitant categories of race, class, and age.”<sup>183</sup> AIDS, then, allowed the media to perpetuate the stereotype of licentious women of color who “deserved” AIDS and the “normal” women who returned to the safety of monogamy in the face of the disease.<sup>184</sup> Even after leaving ACT UP, Juhasz continued to form arguments about representation, deviancy, and AIDS that she did while in the group.

Maxine Wolfe combined the issues of lesbian visibility and media representation in her academic work. In addition to founding ACT UP’s Women’s Caucus, Wolfe was also a professor emeritus in CUNY Graduate School and a coordinator at the Lesbian Herstory Archives. In her 1992 publication on the invisibility of lesbian bars in studies of the “gay community,” Wolfe argued that heterosexist bias in psychology literature left lesbians firmly outside of studies of “women and their environment.”<sup>185</sup> While Wolfe concedes that “historical information” on lesbians “is difficult to locate since much of it has been deliberately destroyed either by governments, by families, or by Lesbians themselves,” she maintained that studying lesbian bars could illuminate the ways the patriarchal control over women’s sexuality manifested in the 1950s and 1960s. These

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<sup>181</sup> Ibid, p. 25.

<sup>182</sup> Ibid, p. 28.

<sup>183</sup> Ibid.

<sup>184</sup> Ibid, p. 32.

<sup>185</sup> Maxine Wolfe, “Invisible Women in Invisible Places: Lesbians, Lesbian Bars, and the Social Production of People/Environment Relationships,” *Architecture & Behaviour* 8, no. 2 (1992): 138.

bars, Wolfe argued, were “sites of resistance,” spurred on the Civil Rights and black power movement, that gave birth to the “overt political movement” of lesbian feminism.<sup>186</sup> Advocating for lesbian visibility in and outside of academia, Maxine Wolfe remained dedicated to fighting the heterosexism that created lesbian invisibility.

Maxine Wolfe also continued to advocate for women with AIDS even after she left ACT UP in 1997 over the split between ACT UP and TAG. Wolfe argued that the people in TAG, like Franke-Ruta, “didn’t do their own research... [but] they were the experts about treatment.”<sup>187</sup> According to Wolfe, the members of TAG “skewered” women with knowledge about HIV/AIDS for not “accept[ing] their point of view.”<sup>188</sup> This went against the very core of ACT UP, in which people could join the organization with no information about AIDS and learn through their participation. “When you worked on an action,” Wolfe recalled, “people made out fact sheets, and you learned that stuff.”<sup>189</sup> When TAG formed, however, this changed and ACT UP became too focused on “knee-jerk politics [in which] people didn’t want to engage with information anymore.”<sup>190</sup> In face of that opposition, Wolfe left the organization.

However, despite leaving ACT UP, Maxine Wolfe was still an activist. In a letter to the *New York Times* editors, Wolfe lambasted their coverage of AIDS treatment that left children, “the tiniest patients,” outside of the scope.<sup>191</sup> In the letter, she reminds readers that in 1997, women accounted for twenty size percent of people with AIDS, “yet

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<sup>186</sup> Ibid., p. 153.

<sup>187</sup> Wolfe, ACT UP Oral History Project, 107.

<sup>188</sup> Ibid., p. 108.

<sup>189</sup> Ibid.

<sup>190</sup> Ibid., p. 109.

<sup>191</sup> Maxine Wolfe, “Women Are Left Out of Hunt for AIDS Drugs,” *New York Times*, September 11, 1997, sec. A30.

virtually no anti-HIV drug has been tested in enough women to assess gender effects.”<sup>192</sup>

The reason for this, Wolfe argued, was the sexism and racism of the medical research industry that led to an overwhelming focus on “white men.”<sup>193</sup> In addition to this focus, Wolfe demonstrated that researchers were also interested in HIV/AIDS in children, but not women. “While it is true that children are not simply miniature adults,” and should thus have separate drug trials to see how drugs work in their bodies, “neither are women living with HIV simply men with different body parts,” Wolfe wrote.<sup>194</sup> So, if children, who made up such a small percentage of people with AIDS, warranted separate clinical trials, as argued by the *New York Times* journalist Wolfe responded to, so should women. And while Maxine Wolfe focused on women in the United States, other activists shifted their focus abroad.

After leaving the HIV Law Project in 1999, Terry McGovern took a position at Columbia University where she advocated for women with AIDS in developing countries. At the Mailman School of Public Health, McGovern served as the director of the Women's Health and Human Rights Advocacy Project and later as the chair of the Heilbrunn Department of Population and Family Health.<sup>195</sup> While at Columbia University, McGovern argued that gender inequality was the root of the AIDS crisis in

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<sup>192</sup> Ibid.

<sup>193</sup> Ibid.

<sup>194</sup> Ibid.

<sup>195</sup> Terry McGovern et al., “As the HIV Epidemic among Young Women Grows, Can We Look to the SDGs to Reverse the Trend?,” *Health and Human Rights Journal* 19, no. 2 (2017): 223.

the Middle East and Africa.<sup>196</sup> By “improving women’s education, workforce participation, and social and political opportunities,” McGovern wrote, developing countries could bolster the fight against AIDS.<sup>197</sup> She further developed this argument and argued that in 2017, the “correlation between human rights violations and poor health outcomes for women and girls” continued to be ignored by the United Nations’ Millennium Development Goals (MDGs).<sup>198</sup> Only when these nations, particularly those in sub-Saharan Africa, addressed their “persistent failures to recognize the sexual and reproductive health and right of women” would health activists be able to adequately address the high rates of HIV/AIDS in women and girls.<sup>199</sup> However, Terry McGovern and other AIDS activists did not only use academia to diffuse ideas about gender and AIDS.

Former AIDS activists, like Karen Ramspacher, Terry McGovern, and Garance Franke-Ruta used the mainstream media to advocate for better treatment of women, those with HIV/AIDS and those without. Karen Ramspacher turned to Oxygen network, a “do-gooder TV network for women.”<sup>200</sup> The network’s founders designed the channel in 2000, according the *New York Times* reporter Alessandra Stanley, to be a “cable network

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<sup>196</sup> Anke A Ernhardt, Sharif Sawires, Terry McGovern, Dean Peacock, and Mark Weston, “Gender, Empowerment, and Health: What Is It? How Does It Work?,” *Journal of Acquired Immune Deficiency Syndromes* 51, no. S3 (July 1, 2009): S96.

<sup>197</sup> Terry McGovern et al., “As the HIV Epidemic among Young Women Grows, Can We Look to the SDGs to Reverse the Trend?,” *Health and Human Rights Journal* 19, no. 2 (2017): 223.

<sup>198</sup> Ibid.

<sup>199</sup> Ibid.

<sup>200</sup> Ramspacher, ACT UP Oral History Project, 44.

for more discerning women.”<sup>201</sup> Ramspacher, who worked as a focus-group researcher for the channel, explained that Oxygen had a “strong advocacy stance” which served to separate it from other networks that targeted women, like Lifetime and Oprah Winfrey’s WE network.<sup>202</sup> Turning from ACT UP to television turned out to be a valuable transition for Ramspacher, who believed that as culture changed, activists needed to also change their tactics. “Every time... the issues will change slightly, the techniques will change slightly,” she explained.<sup>203</sup> Ramspacher felt that activists “should be ever moving forward and continue to care about each other and express it in new and ongoing ways.”<sup>204</sup> Working with Oxygen allowed Ramspacher to enact change in a new way.

Similarly, Garance Franke-Ruta worked in media as a journalist after leaving ACT UP and then TAG, and graduating from Harvard University. Originally planning on becoming a doctor, Franke-Ruta felt like “especially after the new antiretrovirals were approved,” there was less urgency in AIDS activism.<sup>205</sup> So, she returned to her love of writing and earned a degree in English.<sup>206</sup> However, Franke-Ruta did not abandon her political activism, and instead used her experiences with ACT UP to guide her journalism. “I understood what social mobilization looks like, and what its power is,” she told oral historian Sarah Schulman.<sup>207</sup> As a reporter, she witnessed firsthand a

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<sup>201</sup> Alessandra Stanley, “The Oxygen TV Channel Is Bowing to Tastes,” *New York Times*, February 25, 2002, sec. C1.

<sup>202</sup> Ibid.

<sup>203</sup> Ramspacher, ACT UP Oral History Project, 45.

<sup>204</sup> Ibid.

<sup>205</sup> Franke-Ruta, ACT UP Oral History Project, 59.

<sup>206</sup> Ibid., p. 54.

<sup>207</sup> Ibid., p. 59.

“resurgence of... movement-building” in left-wing politics.<sup>208</sup> However, despite this “movement-building,” Franke-Ruta felt “impatient” watching people “complain” without organizing a response.<sup>209</sup> Arguing that she was a more effective activist, Franke-Ruta contended that ACT UP “would have fixed this in, like, six months.”<sup>210</sup> She continued to lament the current state of politics in which “people have their own broader agendas...[who try] to position themselves as intellectuals and as writers, and trying to get jobs with candidates” rather than working against the system to enact change.<sup>211</sup> Through her writing for major publications like *Washington Post*, *Atlantic*, *Washington City Paper*, and *Yahoo News*, Franke-Ruta hoped to “provide a basis for someone to ask further questions” and do something further.<sup>212</sup>

In response to the Trump presidency, AIDS activists increasingly rely on mainstream media to encourage resistance. Terry McGovern contributes to *Huffington Post* to argue for women’s increased access to reproductive health care in a conservative world. Connecting the battle for contraception in the modern political climate to the historic battle for women’s access to birth control, McGovern argued that the United States would regress if the Trump Administration succeeded in allowing companies to opt out of coverage.<sup>213</sup> This attack, McGovern wrote, was “only part of a broader attack

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<sup>208</sup> Ibid.

<sup>209</sup> Ibid., p. 60.

<sup>210</sup> Ibid.

<sup>211</sup> Ibid.

<sup>212</sup> Ibid., 61.

<sup>213</sup> Terry McGovern, “How to End A Positive Health Trend: The Trump Administration’s Plan to Restrict Contraception Is a Step in the Wrong Direction,” *The Huffington Post* (entry), October 17, 2017, [https://www.huffingtonpost.com/entry/how-to-end-a-positive-health-trend-the-trump-administrations-plan-to-restrict-contraception-is-a-step-in-the-wrong-direction\\_us\\_59e67766e4b0153c4c3ec37a](https://www.huffingtonpost.com/entry/how-to-end-a-positive-health-trend-the-trump-administrations-plan-to-restrict-contraception-is-a-step-in-the-wrong-direction_us_59e67766e4b0153c4c3ec37a). Accessed 15 Jan. 2018.

on programs that seek to improve the reproductive health of women and girls, and specifically the most vulnerable among us.”<sup>214</sup> McGovern also decried the administration for expanded President Bush’s Global Gag Rule, which “penalize[d] any aid group” that provided abortion access or information.<sup>215</sup> Calling the Trump Administration “anti-woman,” McGovern wrote that Trump’s actions would result in the deaths of thousands of women and girls due to unsafe abortions.<sup>216</sup> In response to this “hell-bent” effort to “violate the rights of girls and women,” McGovern encouraged readers to “hold tight as science, human dignity, and resistance prevail,” much like the women of ACT UP did in the 1980s and 1990s.<sup>217</sup>

The election of Donald Trump proved to unite activists once again. After the election in 2016, some of ACT UP’s former members banded together and formed the queer activist group Rise and Resist.<sup>218</sup> Originally formed by men from TAG, Rise and Resist recruited Jamie Bauer because of their considerable experience with civil disobedience and activism.<sup>219</sup> Rise and Resist follows in the footsteps of ACT UP and stages direct actions and protests to confront the Trump administration’s immigration policies. Still focused on New York City, Rise and Resist organized a protest in which

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<sup>214</sup> Ibid.

<sup>215</sup> Terry McGovern, “Women’s Health Is Under Threat Everywhere,” entry, *The Huffington Post* (blog), July 7, 2017, [https://www.huffingtonpost.com/entry/womens-health-is-under-threat-everywhere\\_us\\_597211aee4b00e4363df029e](https://www.huffingtonpost.com/entry/womens-health-is-under-threat-everywhere_us_597211aee4b00e4363df029e). Accessed 15 Jan. 2018.

<sup>216</sup> Ibid.

<sup>217</sup> Ibid.

<sup>218</sup> Jamie Bauer, transcript of an oral history conducted in 2017 by Michelle Esther O’Brien, New York City Trans Oral History Project (New York: New York University, 2017), <https://s3.amazonaws.com/oral-history/transcripts/NYC+TOHP+Transcript+015+Jamie+Bauer.pdf>, accessed March 22, 2018, 27.

<sup>219</sup> Ibid.



dozens of protestors stormed the lobby of Trump Tower, unfurling banners that read, “No Ban, No Wall, No Raids.”<sup>220</sup> Other activists threw leaflets from a balcony in the building’s atrium.<sup>221</sup> Jamie Bauer, who organized the protest, told reporters that they protested in honor of their Eastern European Jewish grandparents who came to the United States for “religious freedom and economic opportunity.”<sup>222</sup> The Trump administration’s anti-immigration sentiments, they argued, went against the very foundation of the country. The protest accrued very little media attention outside of New York City, but did end in the arrest of twenty five members of Rise and Resist.<sup>223</sup> Nearly thirty years to the date of ACT UP’s first major demonstration in front of City Hall and Trinity Church, ACT UP’s activists still fight against oppression where they see it.

As women moved beyond ACT UP in response to conflict, they turned to other organizations or careers but remained dedicated to the lessons they learned from the group. In new places, ACT UP’s leading women activists tackle the sexism, racism, classism, homophobia, and heterosexism that fueled that AIDS crisis in the 1980s and 1990s and new crises from the 1990s through the present. A few women turned away from AIDS altogether, but those who did, did so in response to overwhelming grief and loss. Most women from ACT UP, like Alexandra Juhasz, Marion Banzhaf, and Karen Ramspacher took their talents elsewhere and worked with other education and service groups for women and teens with AIDS. The Brooklyn AIDS Task Force, which Juhasz

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<sup>220</sup> Lauren Cook and Allison Fox, “Trump Tower Lobby Taken Over by Protesters; Arrests Made, Cops Say,” *amNew York (Newsday)*, April 13, 2017, <https://www.amny.com/news/politics/trump-tower-lobby-taken-over-by-protesters-arrests-made-cops-say-1.13459852>. Accessed March 22, 2018.

<sup>221</sup> Ibid.

<sup>222</sup> Ibid.

<sup>223</sup> Ibid.

worked with in the 1990s, for example, has changed its name, but endured. Now called Bridging Access to Care, the group is “Brooklyn’s oldest nonprofit prevention, treatment and health service organization, providing comprehensive HIV/AIDS, mental health and substance abuse related services,” focusing on the “under-served racial and ethnic minority communities” of Brooklyn.<sup>224</sup> Likewise, Marion Banzhaf’s Women and AIDS Network still helps connect women with resources. Women from ACT UP learned from their time in the organization and went on to work with other, more specialized organizations to advocate for people with AIDS.

Others activists, like Jean Carlomusto, Zoe Leonard, Catherine Saalfeld, and Maria Maggenti returned to their careers as artists. However, through their art, these women still embraced the tenets of ACT UP, from examining power dynamics and the racism, sexism, and classism within the medical industry, to encouraging women’s empowerment and representation in media. Catherine Saalfeld Gund’s Aubin Pictures, which she founded after leaving ACT UP in 1996, continues to use films to inspire social change. Gund produced the 2017 *Dispatches From Cleveland*, for example, a documentary exploring how the death of her twelve year old son, Tamir, at the hands of the Cleveland Police Department made Samira Rice an activist in Cleveland and nationally.<sup>225</sup> Through Aubin Pictures, an all-women company, Gund also offers

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<sup>224</sup> “Bridging Access to Care, Inc,” <http://www.bac-ny.org/new/>. Accessed March 22, 2018.

<sup>225</sup> Aubin Pictures, “Films: Dispatches From Cleveland,” <https://www.aubinpictures.com/dispatches-from-cleveland/>. Accessed March 22, 2018.

internships to budding female filmmakers in order to educate and inspire women in film.<sup>226</sup> Through the media, women from ACT UP continue to elevate women's voices.

Finally, many women in ACT UP became professors and thus diffused those principles through academia. Terry McGovern, for example, while working as a professor at Columbia University, also serves on the United Nations Reference Group for HIV and Human Rights.<sup>227</sup> Established in 2002, the Reference Group has been largely unsuccessful at directing the United Nations on how to meet the needs of marginalized populations with HIV/AIDS.<sup>228</sup> McGovern, who joined the group in 2010, has since worked to help the larger bodies of the United Nations to understand to important role that gender discrimination plays in preventing women from accessing AIDS treatment and education today. Since 2009, UNAIDS has helped reduce the prevalence of HIV by twenty five percent in the fifteen most affected countries.<sup>229</sup> However, the report, published after McGovern's joining, argues that because more than half of all people with HIV/AIDS in 2010 were female, the UN must increasingly embrace a human rights agenda in order to combat the global epidemic.<sup>230</sup> Committed to ending AIDS by 2030, the organization has a long way to go. The number of reported cases of new HIV infections peaked in 2005 with 1.9 million, but has since undergone a forty-eight percent

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<sup>226</sup> Aubin Pictures, "About," <https://www.aubinpictures.com/mission/>. Accessed March 22, 2018.

<sup>227</sup> Terry McGovern, "Mailman School of Public Health Faculty: Terry McGovern," <https://www.mailman.columbia.edu/people/our-faculty/tm457>. Accessed March 22, 2018.

<sup>228</sup> Lara Stemple, "Health and Human Rights in Today's Fight against HIV/AIDS," *AIDS (London, England)* 22 Suppl 2 (August 2008): S116.

<sup>229</sup> Joint United Nations Programme on HIV/AIDS, *Global Report: UNAIDS Report on the Global AIDS Epidemic 2010* (Geneva: UNAIDS, 2010), 1.

<sup>230</sup> Ibid.

decline.<sup>231</sup> Perhaps if the United Nations continues to embrace this shared understanding of the importance of human rights in the AIDS epidemic, the trend will continue.

Through this process of fragmentation, women brought ACT UP's ideas and more importantly, their ideas about feminism, to new spaces. Despite railing against the increased professionalization of AIDS activists in the early 1990s, many of the women in ACT UP participated in a similar pattern. After burning out, some activists turned to new AIDS service organizations that they hoped could better reach the populations most in need. Others turned to art to showcase the lives of people struggling with HIV/AIDS, along with issues of gender identity, sexual orientation, sex practices, and sexism. Other women, particularly those white, well-educated women who did not have HIV/AIDS, turned to new institutions, from academia to policy-making in the United Nations. The crisis was not fading away into the 1990s despite the hope of better treatments, and in their continued dedication to advocating for people with the disease, women activists turned from experimenting with ACT UP to new places with varying tactics, from filmmaking to publications to continued activism, in order to advocate for women.

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<sup>231</sup> UNAIDS, *UNAIDS Data 2017* (Geneva: UNAIDS, 2017), 4.

## V. EPILOGUE

This thesis demonstrates that women AIDS activists from different backgrounds expanded the AIDS movement through a process of convergence and subsequent fragmentation. Women AIDS activists, some of whom had AIDS themselves, fought for a voice in the male-dominated movement. As women of different ages, sexualities, races, and experiences joined the movement, from professional workingwomen to career activists to working class women, they changed the way the movement worked. Women introduced expert knowledge, language about power and health care, experience with zap action and coalition building, and a practical working knowledge about how AIDS affected women. Women with AIDS and their allies broke the invisibility of women with AIDS and changed the way women receive health care through their activism.

Because of their varied backgrounds and experiences, the women who converged in ACT UP brought new ideas about activism and health care into the group. One of these new ideas was the application of patient empowerment language to people with AIDS that women from the women's health movement brought into the organization. Women in the AIDS movement argued that patients had to possess knowledge over their own bodies and encouraged people with AIDS to confront their doctors when necessary. Women brought this language with them from the women's health movement, which continued to challenge doctors' monopoly of authority on the female body.

Women did more than just bring this language into the AIDS movement—they also combined it with long-established direct action tactics to advocate for change and publicize their message. AIDS activists used boycotts, sit-ins, and demonstrations to

pressure civic leaders not just for city-wide sex education, but sex-positive city-wide sex education that presented the use of condoms and dental dams as both necessary *and* erotic. They demanded not just that women dying from AIDS participate in clinical trials, but that all women should be included. Lastly, they advocated for women to receive their rightful benefits, which the government withheld because of their own sexist understanding of AIDS. And women with AIDS and their allies argued that racism and sexism was the root of inequality in the AIDS crisis while working within a mostly white, male movement. Women united some activists over the causes of sexism and racism, which pushed them into further advocacy and activism outside of the male-centered AIDS movement.

In addition to rooting some of the organization's actions in a longer history of women's empowerment and zap action, women in ACT UP also pushed the organization to expand its scope, audience, and even mediums for activism. Some women, like Risa Denenberg and Maxine Wolfe, pushed the AIDS movement to be more inclusive because of their own experiences with exclusion. Many of these activists were lesbians who had felt excluded in the heterosexual-oriented women's health movement. Other women lived that exclusion every day as poor and working class women, like Katrina Haslip and Zoe Leonard. They connected the political struggle against AIDS with the reality of living with the disease. Through these women, people in the AIDS movement saw the very real results of the Center for Disease Control, Social Security Administration, and Food and Drug Administration's exclusion as women they knew and loved died before receiving care or benefits. Women with AIDS provided living proof of the harm of excluding

women from the AIDS narrative and participated in several AIDS groups to spread awareness and education.

The work of the women in the AIDS movement made considerable, real change for women's health. As an immediate result of Terry McGovern's lawsuit, women with AIDS could receive their rightful care and benefits from the Social Security Administration. And with the help of other activists from ACT UP, McGovern and her clients successfully pressured both the CDC and the FDA to change its policies. The CDC reluctantly updated its case definition of AIDS to include cervical cancer and a t-cell count, both of which gave many women the recognition they needed in order to apply for other local and federal benefits. It also opened up the possibility for more research in AIDS in women's bodies. The FDA, too, changed its policy preventing women of childbearing potential from participating in clinical drug trials. While this change did not force trials to actively include women, it did mean that women could apply to participate in trials to receive potential treatment. These changes were not easily won—women in the AIDS movement fought for years to win these victories for women.

Despite their success, AIDS education and outreach is still an ongoing issue. While Evelyn Hammonds identified the problem with AIDS outreach in African American communities as early as 1987, Cathy J. Cohen argued that African Americans were still largely neglected from the AIDS education conversation in 1999. Despite the some of the successes of the generally white AIDS activists of the 1980s and 1990s, activists and educators have failed to understand that discussing AIDS in black communities required more than an encouragement for safer sex. An AIDS diagnosis, Cohen explained, was influenced by factors of poverty, invisibility, and stigmas

surrounding homosexuality and drug use.<sup>743</sup> Cohen argues that while more African Americans receive AIDS care than ever before, most African Americans still lacked the “political, economic, and social resources necessary” to enact change in their own lives. While women activists during the AIDS crisis highlighted the invisibility and marginalization of black women with AIDS, they did not fundamentally change the social structure that prevented marginalized people from accessing care.

As historian E. Patrick Johnson argues, people of color in the American South are still not receiving the kind of AIDS education necessary to prevent the spread of the disease, which can give some kind of indication at the state of AIDS education across the country. While women of color in the urban north made up the fastest growing demographic group of people with AIDS in the 1990s, currently, people of color in the South are the fast growing demographic. In Johnson’s oral history of gay black men in the South, *Sweet Tea*, he argues that both the media and gay black men blame the culture of “silence around black sexuality” for the rising rates of infection.<sup>744</sup> In some cases, men who have sex with both men and women, but do not identify as gay, do not consider themselves at risk for contracting HIV/AIDS. Because of that, they participate in risky behavior, such as unprotected sex. “A lot of our black women are being infected by men who for whatever reason have not been able to be honest about who they are,” explained one interviewee.<sup>745</sup> Placing the blame for the rise, another interviewee told Johnson that the black community has “misconceptions about what AIDS was and who could get

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<sup>743</sup> Cathy J. Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (Chicago: University of Chicago Press, 1999), 8.

<sup>744</sup> E. Patrick Johnson, *Sweet Tea: Black Gay Men of the South* (Chapel Hill: University of North Carolina Press, 2008), 258.

<sup>745</sup> *Ibid.*, 309.



it.”<sup>746</sup> Decades after the first outbreak in 1981, the public misunderstanding that AIDS was a white gay man’s disease continues to harm women of color.

Despite the ongoing need for increased AIDS education and availability of affordable treatment, the results of the 2016 election served to dramatically change the landscape of the international fight against HIV/AIDS. For example, the Trump administration has effectively disbanded its unpaid commission on HIV/AIDS. The Presidential Advisory Council on HIV/AIDS, which had been in place since 1995 in order to bring people living with HIV/AIDS into the conversation, the Advisory Council may resume in the fall of 2019.<sup>747</sup> This ongoing crisis has frustrated the women activists who pioneered the AIDS movement. While some of them railed against the increased professionalization in the AIDS industry during their time in ACT UP, many have followed in a similar pattern, by working within academia and policy-making. In their oral histories with Sarah Schulman, several women explained how exasperated they feel seeing this ongoing epidemic. Jean Carlomusto believes the reason for the ongoing crisis is society’s continued apathy towards people with AIDS. “Complacency and normalcy... it’s a deadly attitude,” she argued. “All of the social messages that we were trying to get across have just come through with a vengeance... What we need to do more than ever is talk about social issues.”<sup>748</sup> Some participants, like Zoe Leonard, place this frustration on the government. “The big failure is the U.S. Government [sic] and everyone who had the

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<sup>746</sup> Ibid., 313.

<sup>747</sup> Ben Guarino, “Trump Administration Fires All Members of HIV/AIDS Advisory Council,” *Washington Post*, December 29, 2017, [https://www.washingtonpost.com/news/to-your-health/wp/2017/12/29/trump-administration-fires-all-members-of-hiv-aids-advisory-council/?utm\\_term=.47eb67ebd4fc](https://www.washingtonpost.com/news/to-your-health/wp/2017/12/29/trump-administration-fires-all-members-of-hiv-aids-advisory-council/?utm_term=.47eb67ebd4fc). Accessed March 25, 2018.

<sup>748</sup> Carlomusto, ACT UP Oral History Project, 45.

power to make AIDS better and didn't... A lot more people died than needed to die, and a lot more people are today.”<sup>749</sup> And while AIDS has remained a major public health issue in the United States and abroad, the women in ACT UP believed they played an important role in the AIDS movement and that ACT UP greatly improved women's health.

This convergence and fragmentation of feminist and LGBTQ activists provides historians with several important lessons. The very fact of their convergence refutes any notion that the 1970s and 1980s were decades defined by escapism, retreat, and self-interestedness.<sup>750</sup> Instead, this thesis contributes to a growing number of histories that demonstrate that activists learned from the lessons from earlier postwar movements, particularly the women's health movement, and transformed AIDS activism in the public sphere. Activists were committed to women's visibility and even after leaving one form of activism in ACT UP, they still participated in the movement through specialization as activists inhabited new spaces for their advocacy. Terry McGovern is the now chair of the public health program at Columbia University, while Polly Thistlethwaite is the chief librarian at the CUNY Graduate Center.<sup>751</sup> Alexandra Juhasz is also at CUNY, but as the

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<sup>749</sup> Leonard, ACT UP Oral History Project, 65.

<sup>750</sup> In *The Seventies: The Great Shift in American Culture, Society, and Politics*, historian Bruce Schulman argues that in the 1970s, Americans lost faith in public institutions, retreated from the public sphere, and turned inwards. In *Age of Fracture*, Daniel T. Rodgers argues that beginning with journalist Tom Wolfe's 1976 article coining the 1970s the “me decade,” the decade was written off as “an age obsessed with self-referentiality... [and] greed” consumed by a “culture of narcissism.”

<sup>751</sup> Terry McGovern, “Biography,” Columbia University, <https://www.mailman.columbia.edu/people/our-faculty/tm457>. accessed 27 Jan. 2017.

chair of the Film Department at Brooklyn College.<sup>752</sup> Many of the artists in the movement still create pieces about the crisis. Zoe Leonard is a photographer and sculptor, and one of her most famous pieces, *Strange Fruit*, was inspired by her AIDS activism.<sup>753</sup> Jean Carlomusto, too, still makes popular films that feature AIDS and AIDS activism.<sup>754</sup> Generally, the women who participated in the AIDS movement of the 1980s and 1990s are still very much dedicated to the same principles: patient empowerment, health education, and access to care.

Innovative ideas came from women of diverse backgrounds who brought new ideas about health care into the AIDS movement. This diversity informed a more inclusive feminism that took into account how factors of race and class added to women's discrimination. And for women with AIDS, who also experienced discrimination due to their AIDS diagnosis, accessing accurate AIDS information and treatment was nearly impossible. Women from all walks of life responded to this neglect and either became activists or turned their lifelong dedication to activism to HIV/AIDS. Because women in the AIDS movement came from a variety of backgrounds and careers, they converged in ACT UP and built upon one another's knowledge to form a sophisticated and expansive ideology about women and AIDS. This diversity spurred conflict that was necessary for the expansion of ACT UP's scope, but it also led women to turn their energy in new directions. Women in the movement brought their ideas, so essentially shaped by their experiences with other women in ACT UP, into new spaces to more directly reach

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<sup>752</sup> Polly Thistlethwaite, "About," CUNY Academic Commons, <https://pollythistlethwaite.commons.gc.cuny.edu>. Accessed 27 Jan. 2017.

<sup>753</sup> Alexandra Juhasz, "Dr. Alexandra Juhasz, Chair of the Film Department, Brooklyn College," <http://alexandrajuhasz.com>. Accessed 27 Jan. 2017.

<sup>754</sup> Carlomusto, ACT UP Oral History Project, 41.

underserved populations. This process transformed the AIDS movement and changed women's health care for the better.

## APPENDIX SECTION

### AIDS Timeline

June 5, 1981	CDC reports first known instances of severe immune deficiency in gay men
December 1981	CDC reports 270 known cases and 121 deaths from AIDS-related illnesses
January, 1982	First AIDS clinic opens in San Francisco, GMHC founded
September 24, 1982	CDC first uses and defines the term “AIDS,” or acquired immune deficiency syndrome
December 10, 1982	CDC first reports case of AIDS from blood transfusion
1983	CDC first established National AIDS Hotline
January 7, 1983	CDC reports seven cases of AIDS in women
March 4, 1983	4-H established with CDC report identifying homosexuals, heroin users, Haitians, and hemophiliacs at a higher risk of AIDS
May 1983	Congress passes first bill that includes funding specifically for HIV/AIDS (\$12 million to HHS)
May 20, 1983	Scientists at the Pasteur Institute in France discover a virus that may be responsible for AIDS, named Lymphadenopathy Associated Virus (LAV)
September 2, 1983	CDC identifies major routes of infection, eliminating the idea that casual contact could spread AIDS
December 6, 1983	Congressional subcommittee on Government Operations condemns government in <i>The Federal Response to the AIDS</i> for insufficient funding
April 23, 1984	Cause of AIDS identified as retrovirus HTLV-III by Dr. Robert Gallo of the National Cancer Institute
June 1984	Dr. Gallo and Pasteur Institute announce HTLV-III and LAV are almost identical
October 1984	Bathhouses in San Francisco closed by public health officials
1985	FDA licenses commercial blood test for HIV
1985	Congress earmarks \$70 million dollars for AIDS research
1985	Ryan White, a young hemophiliac with AIDS, not allowed to attend school, faces other discrimination
January 11, 1985	CDC expands definition of AIDS
April 15-17, 1985	1 <sup>st</sup> International AIDS Conference, Atlanta
September 17, 1985	Ronald Reagan mentions the word “AIDS” for the first time
October 2, 1985	Rock Hudson dies from AIDS-related illness, established American Foundation of AIDS research (amfAR) in will
1986	Ronald Reagan begins negotiations for the General Agreement on Tariffs and Trade (GATT), intending,

	amongst other things, to protect the interests of American pharmaceutical companies
October 22, 1986	Surgeon General Koop issues report on AIDS
1987	Randy Shilts published his account of the beginning of the AIDS crisis in <i>And the Band Played On</i>
March 19, 1987	Azidothmidine (AZT) released to public, Congress approved \$30 million dollars in emergency funding to distribute AZT
April 1987	FDA releases more accurate HIV blood test
May 16, 1987	US Public Health Service adds HIV to list of “dangerous contagious disease,” barring immigrants with the virus from entering the country
July 1987	Congress passes Helms Amendment, preventing federal funds from being used to promote safe sex AIDS education that included information on homosexuality
October 1987	Activist Cleve Jones’ AIDS Memorial Quilt displayed on the National Mall in Washington D.C.
June 1-3, 1987	4 <sup>th</sup> International AIDS Conference, DC
1988	Congress enacts Health Omnibus Programs Extension (HOPE) Act to increase federal spending on AIDS treatment, education, and testing
May 1988	Surgeon General Koop launches US’s first HIV/AIDS education campaign
October 20, 1988	FDA allowed fast-tracked drug evaluation
1989	Reported AIDS cases in US exceeds 100,000
June 4- 9, 1989	5 <sup>th</sup> International AIDS Conference, Montreal
September 18, 1989	US’s first National Commission on AIDS meets
June 19-28, 1990	6 <sup>th</sup> International AIDS Conference, San Francisco
July 1990	Congress enacts Americans with Disabilities Act (ADA), prohibiting discrimination against people with HIV/AIDS
August 1990	Congress enacts the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, providing \$220.5 million in federal funds for HIV care and treatment
1991	Congress enacts the Housing Opportunities for People with AIDS (HOPWA) Act to provide housing assistance for people with AIDS
January 1991	National Women and HIV Conference, DC
November 7, 1991	Basketball star Earvin “Magic” Johnson announces he has HIV
November 24, 1991	Music superstar Freddie Mercury of Queen dies from AIDS-related pneumonia
1992	AIDS becomes the leading cause of death in men ages 25-44
November 1992	William J. (Bill) Clinton elected president

1993	President Bill Clinton creates the White House Office of National AIDS Policy (ONAP)
June 1993	Congress enacts National Institutes of Health (NIH) Revitalization Act, requiring the NIH to expand its focus to include women and people of color
December 1993	CDC expands definition of AIDS, including a T-cell and cervical cancer to its list of clinical indicators of AIDS
1994	AIDS becomes the leading cause of death for all Americans ages 25-44
February 12, 1994	Pedro Zamora appears on MTV's "The Real World," one of the first depictions of an HIV positive person on reality TV
February 17, 1994	Randy Shilts, author of <i>And the Band Played On</i> , dies from AIDS-related illness
June 1995	"Triple drug cocktail," also known as highly active antiretroviral therapy (HAART) approved and significantly improves the lifespan of people with HIV/AIDS
July 1995	President Clinton's Presidential Advisory Council on HIV/AIDS (PACHA) meets for the first time
October 31, 1995	CDC reports 500,000 cases of AIDS in the US
1996	AIDS is no longer the leading cause of death for all Americans ages 25-44
1996	AIDS becomes the leading cause of death for African Americans ages 25-44
May 20, 1996	Congress reauthorizes Ryan White Comprehensive AIDS Resources Emergency (CARE) Act
October 1996	AIDS Memorial Quilt displayed in its entirety for the last time

## ACT UP Timeline

March 1987	First meeting
March 24, 1987	Wall Street I protest
June 1, 1987	White House protest
June 21-24, 1987	Sloan-Kettering protest
Summer, 1987	Dyke dinners begin
Fall, 1987	Women's Caucus established
January 15, 1988	Cosmopolitan magazine protest
March 24, 1988	Wall Street II protest
April 29-May 5, 1988	9 Days of Rage protest
July 6, 1988	Lesbian Safer Sex Forum
October 11, 1988	"Seize Control of the FDA" protest
November 25, 1988	Trump Tower protest, targeting lack of housing for people with AIDS while wealthy developers got tax breaks
December 15, 1988	NYU Clinical Trials protest
January 19, 1989	ACT UP meets with Mayor Koch's office about housing
January 30, 1989	Kiss-in at St. Vincent's Hospital
March 5, 1989	Women and AIDS Teach-In
March 28, 1989	Second Anniversary of Wall Street protest, 3,000 protestors target City Hall
June 4-9, 1989	ACT UP demonstrates at 5 <sup>th</sup> International AIDS Conference
September 14, 1989	ACT UP protests on the NYSE floor against Burrough's Wellcome
October 31, 1989	Trump Tower II demonstration, in which activists passed out candy and condoms to passers by
December 10, 1989	Stop the Church protest I
January 3, 1990	ACT UP begins a series of three protests in Albany, New York, targeting Governor Cuomo
March 6, 1990	ACT UP forms Needle Exchange Committee
March 28, 1990	ACT UP activists protest in Albany, wrapping Governor Cuomo's mansion in red tape
May 21, 1990	Storm the NIH protest
June 16-23, 1990	ACT UP demonstrates at 6 <sup>th</sup> International AIDS conference
July 1990	<i>Women, AIDS, and Activism</i> published
October 2, 1990	HHS protest (McGovern), DC
October 10, 1990	Needle Rattle/Exchange
November 1990	ACT UP protests Governor Cuomo for cutting AIDS funding by 40%
December 3, 1990	CDC protest, Atlanta
December 8, 1990	Stop the Church II
1991	ACT UP meetings move from Gay and Lesbian Community Center to Cooper Union to accommodate growing numbers



January 23, 1991	“Day of Desperation” protests, targeting media, Wall Street, and city, state, and federal officials for inaction on AIDS
March 1991	ACT UP protests Mayor Dinkins for cutting city’s AIDS funding
September 1, 1991	ACT UP protests outside of President Bush’s vacation home in Maine
September 30, 1991	ACT UP protests at the White House, declaring over 120,000 AIDS-related deaths
January 1992	Members of Treatment and Data Committee (T&D) leave ACT UP to form Treatment Action Group (TAG)
April 4, 1992	ACT UP members meet with President Bill Clinton, who agrees to make AIDS policy a priority

### **Women in ACT UP Timeline**

March 1987	Rebecca Cole joins ACT UP
Summer 1987	Maria Maggenti joins
	Alexandra Juhasz joins
	Maxine Wolfe joins
	Jean Carlomusto joins
	Jamie Bauer joins
	Amber Hollibaugh attends a few meetings, but does not return
May 1988	Polly Thistlethwaite joins
Summer 1988	Zoe Leonard joins
	Heidi Dorow joins
Fall 1988	Catherine Saalfield joins
October 1988	Garance Franke-Ruta joins
1989	Terry McGovern approaches ACT UP to help with her lawsuit
	Katrina Haslip joins
	Iris De La Cruz joins
January 1989	Risa Denenberg joins
1990	Maria Maggenti leaves ACT UP for film school
	Alexandra Juhasz leaves for Brooklyn AIDS Task Force (BATF)
1991	Garance Franke-Ruta leaves ACT UP for Treatment Action Group (TAG)
	Alexandra Juhasz becomes professor of English and women’s studies at Swarthmore College
	Polly Thistlethwaite leaves to return to work full time at the Herstory Archives
	Heidi Dorow leaves and becomes a philanthropy advisor
	Rebecca Cole leaves due to grief and becomes an interior designer

May 1991	Jean Carlomusto directs “L is for the Way You Look,” about lesbian history
1992	Iris De La Cruz died from HIV-related illness Amber Hollibaugh founds the Lesbian AIDS Project at GMHC Catherine Saalfeld leaves due to grief and works as a filmmaker and producer Zoe Leonard leaves due to grief and works as a photographer and sculptor Risa Denenberg leaves due to grief and works as a palliative care nurse
1993	Garance Franke-Ruta begins college at Hunter College, transfers to Harvard University Jean Carlomusto leaves ACT UP and works as a filmmaker and producer Karen Ramspacher leaves ACT UP to focus on service organizations
December 1993	Katrina Haslip dies from HIV-related illness
1994	Marion Banzhaf leaves ACT UP after 076 debacle, works for Florida Department of Health Amber Hollibaugh’s directs and co-produces <i>The Heart of the Matter</i> , about safe sex and sexuality
1995	Jamie Bauer leaves ACT UP Alexandra Juhasz takes job as professor of media history, theory and production at Pitzer College Zoe Leonard premieres her exhibit, <i>Strange Fruit</i>
June 1995	Maria Maggenti’s first film premieres
1997	Maxine Wolfe leaves ACT UP but continues to work as a professor of philosophy Garance Franke-Ruta graduates from Harvard with a degree in journalism, begins working for <i>The Atlantic Online</i> and <i>Washington Post</i> Jean Carlomusto directs, produces, and edits <i>To Catch a Glimpse</i> , about her grandmother’s botched abortion
1998	Zoe Leonard joins <i>Analogue</i> project with the Museum of Modern Art in New York
1999	Jean Carlomusto takes position as professor of media arts at Long Island University Amber Hollibaugh works as a senior strategist for the National Gay and Lesbian Task Force
2000	Karen Ramspacher helps launch the television channel Oxygen Jean Carlomusto directs, produces, and edits <i>Shatzi is Dying</i> , a film about queer history as seen through the eyes of a dog

	Amber Hollibaugh publishes her memoir, <i>My Dangerous Desires: A Queer Girl Dreaming Her Way Home</i>
2002	Polly Thistlethwaite begins work as head librarian of CUNY's Graduate Center
2003	Maria Maggenti begins writing for television shows, including missing persons thriller "Without a Trace" Amber Hollibaugh helps co-found Queers for Economic Justice
2007	Zoe Leonard premieres her photographs for <i>Analogue</i>
2011	Jean Carlomusto directs, produces, and edits <i>Sex in an Epidemic</i> , a documentary about the safer sex movement during the AIDS crisis Risa Denenberg publishes her first book of poetry, <i>what we owe each other</i> , a grief-filled reflection on her time in the AIDS movement
Fall 2011	Alexandra Juhasz begins job at University of Southern California's School of Cinematic Arts
2013	Risa Denenberg publishes <i>In My Exam Room</i> , about her time as a nurse, and <i>Mean Distance From the Sun</i> , about loss and life
2015	Jean Carlomusto directs and produces <i>Larry Kramer in Love &amp; Anger</i> Amber Hollibaugh works as Senior Activist Fellow at the Barnard Center for Research on Women
2016	Jean Carlomusto directs <i>Offerings</i> , about AIDS activists Jean Carlomusto and Alexandra Juhasz collaborate and produce <i>Compulsive Practice</i> , about the daily experiences of living with AIDS Risa Denenberg publishes <i>Whirlwind @ Lesbos</i> , a collection of poems about her lesbian identity
Fall 2016	Alexandra Juhasz moves and becomes head of the film department at Brooklyn College
2017	Maria Maggenti writes screenplays for movies <i>Before I Fall</i> and <i>Dirty Dancing</i>
2018	Whitney Museum of Modern Art produces career retrospective of Zoe Leonard

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