‘Feminists Asleep in AIDS Fight’, asserted the headline of a recent editorial in The Denver Post by Pius Kamau. In his opinion piece written just after the global AIDS conference in Thailand in 2004, Kamau, a thoracic and general surgeon, who was born and raised in Kenya and emigrated to the United States in 1971, called on American feminists in particular to address the ‘feminization of the AIDS crisis in the world’.1 ‘Who better to lead the charge,’ Kamau asserts, ‘than women who have locked horns with the male establishment and won?’2 Kamau calls for the revival of the ‘energetic feminist movement of yesterday to help educate children about HIV transmission and the use of condoms, to mobilize female protest in developing countries and to fight monopolistic pharmaceutical companies for inexpensive drug therapy’.3 He says he’ll never forget the feminist movement of yesterday, which included, for him, ‘the bra-burning, the protest marches, and Betty Friedan’s Feminine Mystique’.4 While his reference to bra-burning reveals a mainstream media-constructed memory of the movement and his reference to Friedan’s Feminine Mystique reveals a sense perhaps of the movement as middle-class and white, and not (yet) radical, nonetheless Kamau has a notably enthusiastic view of the U.S. second wave feminist movement. Because of this movement, Kamau believes, ‘American women are today the most free in the world’, and he wants to remind them that: ‘Women of the world still need you’. According to Kamau, then, where AIDS in the developing world is concerned, to paraphrase Gayatri Spivak, white women need to save brown women from brown men.5

On the same day that Kamau’s editorial was published, a message posted on a women’s studies listserv based in the U.S. contained a link to Kamau’s article, a brief description of his piece, and a request for more information: ‘Pius Kamau claims feminists have ignored the AIDS crisis in Africa. I know this is absolutely incorrect but I do not have the specific information immediately at hand to counter
this claim’. The person who posted the message wanted to know if anyone could point her ‘to research that is women-centered that addresses AIDS in Africa?’ What followed on the women’s studies list was strange, at least to me: there seemed a general agreement that Kamau was right that feminists have ignored AIDS, not just in Africa but throughout the world, and a rather defensive need to explain why. One post asserted that feminists shouldn’t be expected to do everything, echoing a letter to The Denver Post in response to Kamau’s column that noted: ‘There are a lot of bad things happening in the world, and it is not feminists’ duty to be working against all of them, even those bad things where half of the victims are women’.6 The message from the women’s studies listserve seemed to be, to paraphrase Spivak again: white women cannot be expected to save brown women in all the situations in which they need to be saved from brown men.

The post that I was most surprised by, and that I want to focus on to introduce my discussion here, presented a peculiar history of AIDS activism and an equally peculiar history of feminism in the United States. It is this peculiar presentation of history that I am concerned with in this essay, although one could also, of course, critique the peculiar view of contemporary efforts to fight AIDS in Africa that suggests feminism—either a feminism originating in the West or a feminism indigenous to Africa, or one that combines elements of the two—is not an influence on these efforts. It is my aim to look back to a past history of health activism in order to consider how that history might be useful to us now in a different time and in other contexts. I begin with this contemporary discussion of that history to demonstrate first how that history gets remembered, or forgotten, today. According to the post on the women’s studies listserve, the history of the relationship between feminism and AIDS, goes like this:

HIV/AIDS emerged in the West as a STI [socially transmitted infection], which affected white gay men primarily. But the politics of the prevention movement are often overlooked in the question of why feminists didn’t, or don’t, join the struggle on this front.

The first 20 years of sexual politics in the Western HIV/AIDS movement have been dominated by sexual libertarianism and sexual liberalism. As such, it is quite hostile to feminist analyses of sex, gender and sexuality…

The shift of HIV infection from white gay men to black, ethnic minority and indigenous women has meant that women have become more of a
focus now. 75% of HIV is transmitted through penile-vaginal or anal penetrative sex, which makes it impossible for the HIV prevention movement to continue to present the fallacy that sexual behaviour and HIV transmission are unrelated. In the past 5-10 years, there has been an ideological shift away from psychosocial and individualistic explanations of transmission to more structural analyses, which open the door for pioneering feminist interventions.

The author of the post also mentions Gabriel Rotello’s *Sexual Ecology* as a ‘good book discussing the ideology of Western HIV prevention’, and states that the only woman she heard at the Bangkok conference offering ‘a feminist analysis of sexuality’ was Vicki Tallis, who works with BRIDGE, an organization working on gender and development issues and affiliated with the Institute for Development Studies at the University of Sussex in the U.K.

I quote at length from the discussion surrounding Kamau’s piece to demonstrate the extent of the forgetting that surrounds the history of feminist and AIDS activism in the United States in the early days of the epidemic, and especially the forgetting of the intimate and effective relationship between the two. There are many assumptions in the above post, including: that feminists were not, and apparently are still not, AIDS activists; that early AIDS activism in the West was not influenced by feminism; that early AIDS activism did not provide a structural analysis of HIV/AIDS; that contemporary AIDS activism in African countries and the rest of the developing world is not already influenced by feminism; that AIDS activists do not make a link between HIV transmission and sexual behaviour (or, more to the point, specific sexual practices); and that there are no feminists who espouse a position that might be called ‘sexual libertarianism’ or ‘sexual liberalism’. In an email to the women’s studies list submitted after the above post, Judith Lorber offered a protest to the assumptions and forgetting in this discussion by noting, simply, ‘Feminists have been writing on women, sexuality, gender and AIDS for the last 20 years’, and she provided a selected bibliography of some of that work. I want to offer my own protest by beginning to trace a genealogy of feminist AIDS activism. By tracing this genealogy I hope to discern some of the historical ties between feminism and U.S. AIDS activism in terms of political tactics, institutions, and the persons involved in order to investigate the politics of health along with and in relation to the politics of history and memory. The historical memory of the early years of AIDS activism in the United States has been reduced to one figure: the middle-class, gay, white male involved in the AIDS Coalition to
Unleash Power (ACT UP). This figure serves to contain and cover over the complex history of AIDS activism in the U.S. in the 1980s. Just as AIDS was initially identified as a ‘gay disease’, AIDS activism was initially understood as something that only gay men did. Both of these assumptions about AIDS in the early years of the epidemic have had effects, at that time and in the future: on who was diagnosed, and on how the disease was treated, both medically and politically, and on the historical memory of the response to AIDS in the U.S. I believe that by telling a more complex history of AIDS activism at a particular moment in time and in a particular place, we will be better prepared to respond more effectively to AIDS in the present.

Listening for Echoes of Health Activism

How and what we remember has a bearing on the politics of the present, which is why Foucault described his own historical work as an intervention into the history of the present. An important aspect of Foucault’s genealogical methodology is his attempt to discern the discontinuities and surprising continuities of historical events. To locate these discontinuities and surprising continuities, Foucault frequently invokes a method that might be characterized as ‘listening for echoes’. Foucault’s work is frequently criticized for diagnosing a type of power that leaves no space for resistance. Yet all of his work attempts to discern the conditions of possibility for the emergence of new forms of agency. Even in a work like Discipline and Punish where he seeks to describe a new modality of power—the ‘complex ensemble that constitutes the “carceral system”’, a modality of power that doesn’t simply function within the institution of the prison but throughout society—even there, in the midst of his description of a type of power that is all around us, that constitutes us and our relations, Foucault listens for a counter-narrative. In his chapter ‘Illegalities and Delinquency’, Foucault listens for and hears a counter-narrative in the Fourierists’ anti-penal polemics published in La Phalange, which take criminal activities not as ‘monstrosities’, but, according to Foucault, ‘as the fatal return and revolt of what is repressed, the minor illegalities not as the necessary margins of the society, but as a rumbling from the midst of the battle-field’. In Foucault’s genealogical analysis, the ‘lessons of La Phalange were not quite wasted’; their echo was heard, and thus became useful again in the second half of the nineteenth century.
As Joan W. Scott has argued, following Foucault, the concept of the echo does ‘serious analytic work’, helping us to understand both the process of writing history and the historicization of identity categories. In her work, Scott utilizes this concept ‘to demonstrate that feminist identity was an effect of a rhetorical political strategy invoked differently by different feminists at different times’. Scott deploys the term ‘fantasy echo’ to suggest repetitions of identities and modes of political struggle that are ‘not exact’ but still resonate across different times and places. Echoes are not, as is often thought, ‘reproduction[s] of the same’. Rather, they ‘are delayed returns of sound; they are incomplete reproductions, usually giving back only the final fragments of a phrase. An echo spans large gaps of space (sound reverberates between distant points) and time (echoes aren’t instantaneous), but it also creates gaps of meaning and intelligibility’. In this essay, I want to follow the methodological and historical interventions of Scott and Foucault by utilizing the concept of the echo to help theorize the historical relationship between health feminism and AIDS activism. It is my hope that by presenting some of the lessons of early feminist AIDS activists in the United States, that their lessons will be not quite wasted. Indeed, this essay is an attempt to make some of these lessons useful to us again in the beginning of the 21st century.

One lesson of those early feminist health activists that I hope will be not quite wasted is one that I call ‘doing queer love’. This is an historical echo that I believe we must try to hear now, not just in order to challenge a particular history of AIDS activism in the United States, but also in order to provide a model that can be useful for addressing the continuing problem of AIDS across the globe. As I hope to show, ‘doing queer love’ both describes a particular history of health activism and opens up the possibility of bringing into being a different future than the one a conventional history of AIDS seems to predict. In this essay, I trace the echoes between health feminism and AIDS activism in order to present a more complex history of both movements, and to try to think through the ways that the coming together of these two struggles in a particular place and time—New York City in the 1980s—created particular practices of doing queer love that might be effective in other times and places. This may seem absurd. Or even imperialist. After all, queer is a Western identity category, isn’t it?

Yet, illness itself might be understood as queer, and indeed one of the definitions of the word ‘queer’, according to the OED, is ‘not in
normal condition; out of sorts; giddy, faint, or ill’. Illness queers identity categories, and it queers relationships between individuals, communities, and even nations. If we consider queer not in terms of a particular identity, that is, not as a form of being, but as a mode of doing, then we begin to expand the affective and effective possibilities of the concept. So, doing queer as opposed to being queer, and relatedly, doing illness as opposed to being ill. What might it mean to do queer rather than be queer, and how might this doing create new forms of not only queer sexuality, but also queer love, in this case within the particular domain of the politics of health and illness? By queering love rather than or as well as sexuality, the concept of queer, and its multiple lessons and uses, expands. I contend that doing queer love provides a framework through which we might respond both politically and personally to the stigma and shame attached to an illness like AIDS, even in contexts where it is transmitted mainly through heterosexual sex. In making this argument, I consider AIDS activism in terms, as Foucault would have it, of a way of life as opposed to an identity.

Queer Ascesis

In his essay ‘The Subject and Power’, Foucault explains that the main objective of his work ‘has not been to analyze the phenomenon of power’, but rather ‘to create a history of the different modes by which, in our culture, human beings are made subjects’. His three volume *History of Sexuality* might be understood, then, as a history of the modes by which human beings are made and make themselves subjects within the ‘domain of sexuality’ during different historical moments and in different cultures. For Foucault, the task of the philosopher is ‘to investigate not only the metaphysical systems or the foundations of scientific knowledge but a historical event—a recent, even a contemporary event’. Foucault marks the beginning of this shift in the philosopher’s task—from investigating metaphysical systems and foundations of knowledge to investigating an historical event—in a fairly obscure text published by Kant in a Berlin newspaper at the end of the 18th century and entitled ‘What is Enlightenment?’ According to Foucault’s reading of Kant’s text, the question for Kant is not Who am I?, as it had been for Descartes, but ‘What are we? in a very precise moment of history’. I want to ask this question—What are we?—in the very precise moment of the emergence
of AIDS activism in the mid to late 1980s in the very precise place of New York City. I want to ask this question about New York City in the 1980s both so that we might know something more or else about that illness event, and so that we might know something more or else in anticipation of future illness events in other places.

In an interview for the French gay magazine, *Gai Pied*, that appeared in April 1981, Foucault also discusses this ‘problem of the present time, and what we are, in this present moment’, in particular with regards to the event of a particular form of doing social relations and subjectivity that we call ‘homosexuality’. Foucault expressed concern for the tendency to ‘relate the question of homosexuality to the problem of “Who am I?” and “What is the secret of my desire?”’ Instead, Foucault thought it ‘better to ask oneself, “What relations, through homosexuality, can be established, invented, multiplied, and modulated?”’ Such a rethinking of the homosexual self not in terms of the truth of one’s identity but rather in terms of one’s becoming through relations led Foucault to speculate on the radical potential of friendship between men. For him, the ‘neat image of homosexuality’, which emphasizes the immediate pleasure of ‘two young men meeting in the street, seducing each other with a look, grabbing each other’s asses and getting each other off in a quarter of an hour’, does not generate unease, despite assertions (from the religious right especially) to the contrary. What makes homosexuality more ‘disturbing’, according to Foucault, is its ‘mode of life, much more than the sexual act itself’. Foucault is not interested in defining once and for all a specific mode of life, but rather he encourages what he calls ascesis, which he delineates as ‘the work that one performs on oneself in order to transform oneself or make the self appear which, happily, one never attains’. Foucault wonders if we might create or invent—not discover, which would imply some true identity—a homosexual ascesis or mode of life.

He notes that women have been more able to do something like this in the past because physical contact between women is more tolerated, and he discusses Lillian Faderman’s historical account of romantic friendship and love between women as demonstrating the way such a mode of life is invented through intimate gestures. Foucault claims that ‘[m]an’s body has been forbidden to other men in a much more drastic way’, insisting that only during war do men have the kind of intimacy that is allowed more generally between women. There are certainly problems with Foucault’s schema: on the one hand, although certain personal or private intimacies between women may have been
more tolerated historically, I do not at all think that women’s social or political movements, for example, which we might understand as expressing a kind of intimacy, have been encouraged or even tolerated; and on the other hand, there are many more domains in which men engage in homosocial, if not explicitly homoerotic, bonding than Foucault acknowledges, including sports, social and business clubs, and, even, many professions that are predominately male. Nevertheless, his interest in the ethics of a particularly gay way of life that is inventive and remains open to new relationships and new social spaces anticipates for me what emerges with, or in response to, AIDS in the gay and lesbian community. Foucault might have been talking about the history of AIDS and AIDS activism when he noted: ‘We have to dig deeply to show how things have been historically contingent, for such and such reason intelligible but not necessary. We must make the intelligible appear against a background of emptiness and deny its necessity. We must think that what exists is far from filling all possible spaces’. Foucault discussed ‘friendship as a way of life’ just as AIDS was emerging and just as feminism was being transformed in crucial ways: all around 1981. I contend that around that same time, through the experience and event of AIDS in the gay community in the United States, a queer ascesis was invented or came into being, through not only the friendship and love between gay men, but between gay men and lesbians.

Beginnings 1: The Origin Story of AIDS Activism in the United States

Although most histories of AIDS in the West begin around 1981, histories of AIDS activism in the United States often begin with the creation of the AIDS Coalition to Unleash Power (ACT UP) in New York City in 1987. Prior to 1987, it is believed that the gay community responded to AIDS through practices of accommodation, not practices of politics. In this prevailing narrative, politics only emerges after the failure of accommodation. Practices of accommodation, on the one hand, as exemplified by many of the policies of Gay Men’s Health Crisis (GMHC) founded in New York City in 1982, sought to establish a network of services for people with AIDS. This network of services, established initially by and for the gay community, provided resources for caring and strategies for coping with the realities of a terrible new disease that was killing virtually everyone who became
ill. For example, GMHC introduced the AIDS Buddy program to provide practical assistance for people with AIDS in their own homes, a program which I would describe as an early form of doing queer love. Practices of political confrontation, on the other hand, sought to challenge the denial of the crisis by the United States government and the ‘general public’ and to insist that the government’s failure to respond meant that it was abetting, if not outright committing, genocide against the gay community. Or so the story goes.

From the beginning, this origin story of AIDS activism has been challenged. In a collection of her journalism from the 1980s, writer and political activist Sarah Schulman notes in her introduction: ‘Contrary to the recent periodization of the history of AIDS activism, there was resistance and political rebellion before the founding of ACT UP’.

Similarly, in Globalizing AIDS, Cindy Patton asserts that while ‘ACT UP reintroduced agitprop into a rather bland political scene, … activism began when the first living person was acknowledged to have an unnamed but recognizable syndrome and had to cope with a hostile medical system’. And, more recently, in interviews for the ACT UP Oral History Project, many interviewees, including Jean Carlomusto and Gregg Bordowitz, are keen to discuss their own AIDS activism before the formation of ACT UP. Nonetheless, the narrative that begins with accommodation, then moves into confrontation, and often ends with the arrival of the protease inhibitors and successful forms of treatment remains the hegemonic historical narrative of AIDS in gay communities in the United States.

Like Schulman and Patton, I want in this essay to challenge that hegemonic historical narrative of AIDS activism. The purpose of my challenge is not to revise the understanding of Gay Men’s Health Crisis as sometimes accommodationist, nor to claim that ACT UP wasn’t one of the leading actors in bringing AIDS to the forefront of the American social and political landscape, and to the consciousness of the American people. Rather I want to trace a genealogy of AIDS activism by moving back from 1987 and ACT UP’s emergence in order to consider some factors that led to that emergence. Some of these factors are widely known, like Larry Kramer’s frustration with and eventual exile from GMHC; but others are less acknowledged, even forgotten, as the discussion on the women’s studies list indicates, such as the influence of the women’s health movement on the forms of activism that emerged with AIDS from the very beginning, not just with ACT UP. In particular, I want to analyze the link between feminism and AIDS activism, and the articulation of a queer
ascesis that such a link brings into being, by considering three figures—Sarah Schulman, Ann Cvetkovich, and Gregg Bordowitz—whose work both remembers and continues to perform this link. Schulman, Cvetkovich, and Bordowitz have all sought to document the affective and effective histories of AIDS activism. Their multiple practices—combining art, theory, and oral history—are modes of doing queer love.

Beginnings 2: ‘We Like Dykes!’

In My American History, Sarah Schulman presents what she knows is not a typical account of lesbian and gay history, never mind American history. To explore American history in the Reagan and the first Bush years, Schulman first looks back to feminism in the U.S. in the 1970s, its influence on her own theories and practices, and the way it gets remembered in the 1980s and after. In her introduction, she notes that feminism in the 1970s has been historically revisioned as, paradoxically, ‘either dominated by dogmatic and prudish lesbians or deeply homophobic’. Although she acknowledges that some larger feminist organizations ‘were the site of well-known lesbian purges’, she regrets that the dominant account of seventies feminism does not at all capture her own experiences within the diverse and vibrant movement that was ‘engaged in re-evaluating and re-imagining every aspect of social life’. Seventies feminism, as Schulman describes it, exemplifies many of the practices and new forms of relations that Foucault encouraged in the interview from 1981. According to Schulman, the practitioners of seventies feminism ‘opened up new venues for the imagination as they asserted women’s lives and lesbian lives as justifiable terrain for autonomous political organizing, challenged male power and hegemony, raised consciousness, and learned to re-conceptualize the social and physical functions and the desire of the female body’. Schulman delineates a shift in feminism around 1980 that coincides with the rise of Reaganism and the New Right in the United States, one that we might today describe as the emergence of a neoliberal feminism ‘focused more on cultural expression and less on direct action’. Despite this shift, Schulman, who presents a Foucaultian-style genealogy in her own right, acknowledges echoes of seventies feminism in the emergence of AIDS activism in the 1980s. Indeed, I would argue that many feminists, who were driven from, or simply left, the ‘mainstream’ feminist movement for various reasons in the
early 1980s, continued to work to reconceptualize the interrelationship between gender, race, class, and sexuality within the domain of AIDS activism. Amber Hollibaugh explains in an interview about her involvement in AIDS activism that ‘AIDS activism as a movement valued my ability to do explicit work around sexuality’.\(^3\) Having just experienced the ‘sex wars’ that erupted in the U.S. women’s movement at and after the Barnard Conference on Sexuality in 1981, Hollibaugh was ready to participate in a political movement that valued her ability to ‘talk about sexuality as part of class and race’.\(^4\)

Around the same time, both Schulman and Maxine Wolfe found themselves estranged, as lesbians, from the reproductive rights movement in New York City, and they, like Hollibaugh, moved into a movement that needed them and the skills they had learned in the women’s liberation movement. Wolfe was one of the early leaders in ACT UP, and brought a long activist past to the group. She was one of the few ‘older’ members of ACT UP, becoming involved when she was in her 40s, and continuing to participate in the group for over ten years. In an appreciation of Larry Kramer entitled ‘The Mother of Us All’, Wolfe acknowledges Kramer’s importance to early AIDS activism, but also suggests that what was unique was the genetic contribution of each of them to the newly-born movement:

Recently, I learned that some ACT UP members would affectionately describe Larry Kramer and myself as the “father” and “mother” of the group, though it wasn’t always clear who was who. Though Larry can lay claim to taking part in ACT UP’s birth, I cannot. I never even heard of Larry Kramer before my first ACT UP meeting in late June 1987, three months after the group started. Both of us were connected to that elusive entity called “the community”, but our worlds were far apart: Yale vs. CUNY; the West Village vs. Brooklyn; the New York Native vs. Womanews; gay man with no radical history vs. lesbian with lots of it, especially on the left, in the women’s and lesbian feminist movements.\(^4\)

What was new in early AIDS activism, as Wolfe’s statement implies, was not the discourses, tactics, and institutions that the movement brought into being, but the social and economic capital that gay men brought to such a movement. Or, as Schulman puts it: ‘The coming together of feminist political perspectives and organizing experience with gay men’s high sense of entitlement and huge resources proved to be a historically transforming event’.\(^4\)

Schulman’s journalism from the period shows that lesbian feminists offered early personal and political support for gay men
experiencing AIDS and the hysteria surrounding it. In an article from December 1985 in *The New York Native* entitled ‘Becoming an Angry Mob in the Best Sense: Lesbians Respond to AIDS Hysteria’, Schulman describes the challenges both lesbians and gay men face as a result of ‘the new homophobia accompanying AIDS hysteria’. She acknowledges that relationships between gay men and lesbians, while often individually quite satisfying and emotionally important, have been at the community level more constrained and ‘historically tenuous’. Nonetheless, as she maintains in the opening sentence of her piece, ‘We’re in this together now’. What follows this assertion is a feminist analysis into the rather muted response by the gay male community in New York City to the closing of the baths, and the surprisingly interested (and hardly prudish) response by several well-known lesbian activists. Writer and activist Jewelle Gomez, for example, tells the *Native* that “closing baths and bars is the first sign of political repression. Whether we think bars and baths are wonderful or not, they’re not going to stop with the bars. We can’t pretend that and still be self-respecting”. And Joan Nestle, writer and co-founder of the Lesbian Herstory Archives, worries about being “lulled into a circle of respectability”. Nestle links the failure to mount strong protests against the bath closings to a ‘state of shame’ in the gay and lesbian community. “Are we willing to fight for sexual territory that we are being told is death?” she asks. Nestle demonstrates that when trying to counter the paralysis that sometimes accompanies shame, it helps to know one’s history: “When I saw the television and I saw policemen standing in front of the bar, it came home to me that this was a fifties image”. Schulman explains that ‘Nestle expressed a belief that a grassroots movement would develop from these events’, and her piece ends with a quote from Nestle calling for a reemergence of the activism of her (women’s and gay liberation) past: “There’s really a chance for street responses like we used to have, by an angry mob. I think we have the potential to be an angry mob and I say that in the best sense of the word.” Nestle’s connection between history, shame, and the potential of the angry mob anticipates Eve Sedgwick’s later theorizing about the importance of the negative affects, in particular shame, for bringing into being a queer politics.

Schulman’s later commentary on this piece notes the irony in the fact that ‘[a]lthough lesbians are constantly portrayed in the straight and gay media [and, I would add, even at times on women’s studies listserves] as prudish and anti-sex, clearly grass-roots lesbian activists were a lot more willing to go on record as opposing the closing of the
baths than a good percentage of the gay male leadership’. Schulman also contends that while gay men were largely apolitical, lesbians had the critical and practical tools to confront institutional power. Because of their access to greater resources and positions of power, gay men believed that they were included in the ‘general public’, and that their needs would and should be met. Many lesbians, according to Schulman, were ‘clear on their exclusion from the beginning’, and this exclusion gave them a better view of the workings of power. She acknowledges again that some lesbians resented gay men for their sense of entitlement and lack of sociopolitical critique, but she also notes that other lesbians ‘did not hold grudges, or were willing to work hard to build a more enlightened and effective community’. Schulman’s notion of an ‘effective community’ captures, I think, the way that, in early AIDS activism, lesbian and feminist activists became useful to gay men in ways that neither group had imagined before. The lessons many lesbians had learned in the 1970s echoed into the 1980s in the domain of AIDS activism. I don’t mean to imply that lesbian and feminist activists were used by gay men in a sort of mercenary fashion, although some might make this argument. Rather I want to consider how relations, between the ‘general public’ and gays and lesbians, as well as among and between gays and lesbians, get enacted through an event like AIDS, and to suggest that usefulness can be a means through which we create not only effective but also affective communities; it can be a means through which we begin to do queer love.

In People in Trouble, her novel depicting the early years of AIDS in New York City, Schulman portrays the emergence of just such a queer sort of love. Kate, one of the narrators of Schulman’s book, describes the make-up of the ACT UP-like organization, Justice:

No straight men showed up at all.

“Straight men don’t know how to take care of other people,” Daisy explained. “And they don’t work well in groups”.

There was a band of veterans from the now defunct women’s liberation movement who were the only ones who had been consistently politically active for the last decade, and so knew better than anyone else how to make flyers, how to do phone trees, the quickest way to wheat-paste, and who weren’t afraid of getting arrested.

“Being a woman in Justice means being in leadership,” Daisy once said. “As soon as you walk in the room all the guys turn around and say, ‘Now what?’”

“We like dykes,” the guys would chant every once in a while when the women did something really great.
In her journalism and her fiction from the period, Schulman reveals that lesbians and feminists were important players in the early AIDS movement, and that the AIDS movement brought gay men and lesbians together in remarkable ways, creating new forms of relationships, new kinds of love.

Echoes 1: Seizing Our Bodies and the FDA

As the main interviewer for the ACT UP Oral History Project, Schulman continues to do queer love, by documenting both the historical links between AIDS activism and other political movements and forms of activism, as well as the affective experiences that come with political activism, especially political activism haunted by so much loss. Queer love, as practiced by Schulman, becomes an historical methodology, which is itself a form of politics. The ACT UP Oral History Project, then, presents both effective and affective histories; that is, histories that are attentive to the rhetoric and practice of politics and movements for self-determination, as well as to the poetics and practices of suffering and love. Although in many of the interviews AIDS activism is understood within a long history of struggles by minority groups for civil rights and self-determination, I want to continue to focus here on what I am arguing is an explicit connection between AIDS activism and the health feminism of the 1970s. Indeed, Schulman herself embodies this connection, and through her we hear the echoes that link the two movements.

In response to Schulman’s question about ‘ACT UP’s greatest achievement and biggest disappointment’, Gregg Bordowitz says, ‘The biggest achievement was the idea that people with AIDS should be in control of the decisions that govern our treatment and cure. It's the one thing I return to, that principle that the people with the disease should be at the center of a discussion about the disease. No more of this notion of patients being taken care of, that patients play an active role in their care. All of that self-care stuff was really important. I think that was the lasting contribution’. Bordowitz is certainly right that ACT UP emphasized these things, and he acknowledges elsewhere in his interview the influence of other political fights on ACT UP’s theories and practices. What rarely gets recognized explicitly is the continuity between ACT UP’s theoretical critique and its political tactics and those of the women’s health movement. If we look back to, for example, the introduction of
Claudia Dreifus’s 1977 edited volume, *Seizing Our Bodies*, the echoes between the movements are obvious.56

As the title of Dreifus’s edited volume suggests, one of the main goals of the women’s health movement was to provide women with the tactics and tools to seize control of their own bodies from institutions, such as medicine and the law, as a means to liberation. Health feminism was concerned with women’s often negative experience of medicine, and in particular gynecology. The ‘radical, anarchic’ movement distrusted organized medicine, and offered an early critique of the medicalization of supposedly ‘natural’ experiences, which resulted in, for example, the transformation of childbirth into an increasingly technological experience in the hands of usually male obstetricians.57 The women’s health movement established both consciousness-raising groups, in which ‘expert’ medical knowledge could be shared beyond the small coterie of medical professionals, and self-help clinics, which encouraged patient involvement in diagnosis and treatment. As Dreifus explains, these clinics, which would become the Feminist Women’s Health Centers, ‘often employ staff physicians’, but also ‘uniformly have women, often nonprofessionals, doing the bulk of the medical service; their emphasis, always, is on patient involvement in diagnosis and treatment, on deprofessionalization of services’.58

Just as importantly, and also as a means to raise consciousness about the politics of women’s bodies, the women’s health movement used direct action tactics to disrupt the specific institutions that affected women’s experiences of their bodies. For example, a group of health feminists disrupted the Senate hearings on the safety of oral contraceptives in 1970.59 As Judith Coburn explained at the time, ‘We went to the hearings to protest the alliance of drug companies, population control experts, and the government, an alliance we believe has given the Pill a clean bill of health at women’s expense’.60 Although AIDS activists would demand something somewhat different from the drug companies and the government than was demanded by those women who disrupted the Senate hearings, the notion that one might challenge specific government institutions making health policy, like the Food and Drug Administration, was part of the politics of feminist health activism at this time.61

When Sarah Schulman asks Gregg Bordowitz to describe some of the big actions that he worked on for ACT UP, he says that the most important one was the non-violent takeover of the Food and Drug Administration. According to Bordowitz, David Barr and Mickey
Wheatley came to him to propose this action on the floor of an ACT UP meeting, and their rationale for the action won Bordowitz’s support. Bordowitz explains to Schulman that Barr and Wheatley told him, “‘Look, we have this idea for a strategy that would be very different than things that have been tried before in activism. Millions of groups, not millions that’s an exaggeration, but many groups have gone to Washington and protested in front of the White House. Many groups have protested in front of Congress. For our movement, we need to go to the Food and Drug Administration. This is very specific. This is an institution that is very specific to the issues that we’re facing’”62. The demand of this action, according to Bordowitz, was both to ‘cut through the bureaucratic red tape of the Food and Drug Administration’ and to emphasize ‘that people with AIDS should be involved in every level of decision-making concerning research for a treatment and a cure for our disease’.63

Bordowitz goes on to explain that he came up with the slogan for the action—‘Seize Control of the FDA’—which, he says, ‘was frightening to many people, this notion of seizing control. But’, he continues:

I was very insistent: ‘This is what has to be. It has to be that we are just going to take over the agency. The agency is not being run in our interests. People with AIDS are going to take over the agency and run it in our own interests’. This is very much the idea, which I think was the lasting historical contribution of ACT UP, that people with AIDS be in control of all decisions concerning our health. It was very significant and it’s very consistent within the history of civil rights movements. Primarily, the core principle is self-determination. So this is self-determination for people with a disease. But it’s also the heart of the union movement: self-determination for workers to run their work life; the civil rights movement, self-determination of people of color; feminism; gay and lesbian liberation. It’s consistent, and you can see actually our demand, as activists, as people with AIDS, or supporters of people with AIDS in the AIDS activist movement is completely consistent with the history of civil rights.64

At the same time as Bordowitz is asserting the originality of ACT UP’s strategies and tactics, he acknowledges that it is continuous with and echoes a long history of other movements for self-determination. This is what is forgotten in both the hegemonic narrative of AIDS activism that posits such activism as emerging with ACT UP and the feminist narrative I opened this essay with that sees no direct connection between the two movements, theoretically, strategically, and in terms of membership. Feminists and gay men were able to create an
‘effective community’ precisely through political struggle that, while concerned with AIDS in the present, also remembered and made connections to struggles for self-determination in the past, through the participation of lesbians in particular. Listening for these historical echoes in the present helps us to imagine into being new forms of health activism for the future.

Echoes 2: Doing Queer Love Through Oral History

Schulman’s journalism and fiction from the period, and her contemporary oral history work, attempt to counter the loss of this continuity, the silencing of these historical echoes, and, in so doing, attempt to recover, or more likely reinvent, an effective community among lesbians and gay men. According to Schulman, she and filmmaker Jim Hubbard began their video oral history project because she ‘had long been disheartened by the false AIDS stories told in the few mainstream representations of the crisis’. In these false AIDS stories, AIDS activism and the love among gay men and between gay men and lesbians never existed; instead, only once the ‘general public’ ‘came around’, was AIDS finally addressed, in the U.S. at least. It should be noted that, in many respects, these false AIDS stories are perpetuated not just by the mainstream media, but also by some feminist and gay and lesbian histories. What Schulman wants to communicate through this project is ‘what really took place’: ‘thousands of people, over many years, dedicated their lives to achieving cultural and scientific transformations’. We’ve got to look back at the history of AIDS activism to attempt to recover the evidence—of these cultural and scientific transformations, and of the creation of affective and effective communities.

Historian John Howard has noted that oral history has been a particularly ‘vital methodology’ for gay and lesbian and queer history. According to Howard,

Gay persons who have gone through the stereotypical trajectory—from country to city, from ‘closetedness’ to ‘awareness’—those who are strongly self-identified as gay and highly politicized make excellent oral history narrators. They understand the need for such studies. They feel compelled to participate and often do so via urban-centered, community-based oral history projects, some of the earliest of which were undertaken in Boston, Buffalo, San Francisco, and Toronto.
In his own work, however, Howard wants to supplement these studies that focus on this ‘stereotypical trajectory’ with a study that offers a different trajectory, or that recognizes that this is not always or the only trajectory for queer people, especially in the American South. As a method for documenting both the hegemonic and the nonhegemonic stories, oral history also seems to be a particularly vital methodology for the history of AIDS activism; it is a method well suited to capturing both the effective and the affective dimensions of this history. Doing oral history might itself be a way of doing queer love.

Like the ACT UP Oral History Project, Ann Cvetkovich’s own ACT UP oral history project discussed in her recent book, *An Archive of Feelings*, seeks to counter a mainstream memory of the movement, which, as it purportedly remembers that movement, paradoxically forgets its complexity. Cvetkovich is interested, therefore, in documenting, in particular, lesbian involvement in ACT UP because, she fears, ‘with the passage of time, ACT UP is in danger of being remembered as a group of privileged gay white men without a strong political sensibility, and sometimes critiqued on those grounds’. Again, the figure of the middle-class, gay male as AIDS activist ends up screening our memory of the moment and its complexity. It is perhaps not surprising, considering the devastation in the gay community wrought by AIDS, that two lesbian writer/scholar/activists should take responsibility to witness to the early years of AIDS in the United States through oral history projects. Indeed, as both Schulman and Cvetkovich understand, part of the reason lesbians play a significant role as witnesses to the AIDS crisis, is because most of those lesbians who participated in AIDS activism have survived to witness to the event, while so many of their gay companions in AIDS activism did not. This phenomenon itself—gay men dying and lesbians surviving and becoming witnesses—becomes part of the event of AIDS that must be witnessed.

Like the ACT UP Oral History Project, Cvetkovich’s oral history of ACT UP’s lesbians is an attempt to present a broader history of AIDS activism that emphasizes both the effective and the affective components of activism. Schulman and Cvetkovich as oral historians are part of the genealogy of feminist AIDS activism that I want to trace in order to remember past methods of doing queer love, and in order to bring others into being. Although perhaps inspired and influenced by each other, the preoccupations that Schulman and Cvetkovich bring to their interviews are somewhat different. I want to point briefly to these differences in order to highlight once again the fact that there is
no one story of AIDS activism, and to note that there is still much work to be done to document the multiplicity of AIDS activism in particular and forms of doing queer love more generally.

Schulman discusses the personal relationships that formed as a result of ACT UP, and she is clearly interested in, and gets many of her interviewees to talk about, the fact that several gay men had sexual relationships with both straight women and lesbians in ACT UP. Indeed, Schulman and several of her interviewees discuss Gregg Bordowitz, in particular, as the ‘lesbian boyfriend’. Schulman certainly understands that the possibility of a more fluid understanding of sexuality was part of what made ACT UP revolutionary, but at the same time I maintain that she is preoccupied more with the drama of direct action than with the drama of sexual action. Schulman tries hardest to get her interviewees to speak about ACT UP’s countless protests, and the myriad organizational details that brought these protests to fruition; she seems more concerned with gathering evidence of ACT UP as an effective community than as an affective community. She is also concerned with how each interviewee came to be an activist, and what particular organizational, artistic, or performative talents they brought to ACT UP, or how they discovered these talents through ACT UP. There is no doubt that she herself knows a much longer history of struggles for self-determination, as Bordowitz would have it, but she wants to get at whether or not her interviewees located themselves within this longer struggle before they came to ACT UP, either actively through past activism, or intellectually through knowledge of the history of such struggles.

Cvetkovich, on the other hand, is preoccupied with presenting an affective history of ACT UP. Although her work, like Schulman’s, presents the transformation of politics and science brought about by ACT UP, she is equally, if not more, curious about the transformation of desire and the experience of loss that took place within ACT UP. For Cvetkovich, oral history has the radical potential to document not only the political achievements of ACT UP, but its failures: most acutely, the failure to save the lives of so many who died in the early years of the epidemic, in spite of AIDS activism, and the forms of love it brought into being. Cvetkovich explains that oral history documents ‘lost histories and histories of loss’, and she says her goal is ‘to use interviews to create political history as affective history, a history that captures activism’s felt and even traumatic dimensions’. Cvetkovich is surprised to discover a gap between ‘ACT UP’s professed reputation as a model for queer intimacies, and the actual
practice, which involves a lot of secrecy’. ⁷¹ She explains that in her interview with Zoe Leonard, one of Bordowitz’s lesbian girlfriends, Leonard distinguishes between ‘oral history as witnessing and oral history as confessional, suggesting that the narrative of one’s sexual life in ACT UP might be an important story of personal growth, but not necessarily one of public or collective significance’. ⁷² Although I think Leonard is right that what matters is not the individual sexual relationships between gay men and lesbians that ACT UP spawned, but the ‘larger picture of AIDS’, I also think that we might understand doing queer love as a model of witnessing that combines the preoccupations of both Schulman and Cvetkovich, and indeed that is, simply put, preoccupied: preoccupied with doing politics and history, and with the effective and affective dimensions of both. By doing queer love through oral history, Schulman and Cvetkovich are digging deeply, but also showing that things are historically contingent, as Foucault would describe his own method. Neither Schulman nor Cvetkovich offers a definitive history. Rather both seek to counter the forgetting of the political and emotional complexity of the early years of AIDS activism in the United States, and to remind us of the many ways the political relates to the emotional. Their work is meant to inspire further work to trace connections: between lesbians and gay men, between past and future struggles for self-determination, between political protest and sexual desire, and between being at a loss and doing queer love.

**Echoes 3: From New York City 1989 to Durban, South Africa 2000**

I want to conclude with a final echo, and a sign that doing queer love might be a model that can travel to other contexts. When we consider the ways that doing queer love as an affective and effective strategy for confronting AIDS might travel and be translated, we need to recall Scott’s point that, because echoes span gaps in space and time, they also create ‘gaps in meaning and intelligibility’. ⁷³ As Scott contends, these gaps are necessarily transformative, and as such they are potentially productive of new discourses, practices, and institutions. I want to conclude by listening again to Gregg Bordowitz, not this time as one of Schulman’s interviewees in the ACT UP Oral History Project discussing the way ACT UP took up and transformed the strategies of other movements, nor as the ‘lesbian boyfriend’ also discussed in

Lisa Diedrich
Cvetkovich’s archive of the feelings of political activism, but as an artist and activist involved with Testing the Limits, a collective of video artists formed in the spring of 1987 ‘to document emerging forms of activism developed in response to government inaction about the global AIDS epidemic’. In ‘Picture a Coalition’, an early statement about the importance of this video work, Bordowitz states that ‘[p]eople must be able to see themselves making history. People living with AIDS must be able to see themselves not as victims, but as self-empowered activists’. Bordowitz’s 1988 essay ends with the repetition of the phrase ‘picture a coalition’, which is a performative gesture that suggests how and why we must do queer love: ‘The most significant challenge to the movement is coalition building, because the AIDS epidemic has engendered a community of people who cannot afford not to recognize themselves as a community and to act as one’. The sense that people with AIDS must recognize themselves as a community and act as one was necessary in New York City in 1988, and it is still necessary today, within New York City and beyond it.

Bordowitz’s later videos and writings attempt to continue to picture a coalition, in particular between New York City in the 1980s and South Africa in the first decade of the 21st century. In the essay, ‘More Operative Instructions’, he describes the structure of his recent video, Habit (2001), which is organized in three sections that ‘explore the themes of habit, foreignness, and intimacy’. Bordowitz first wants to show the distance between him, a relatively privileged person with AIDS (PWA) in the United States, and many PWAs in South Africa, who do not have access to the treatments that Bordowitz has had access to, but who Bordowitz nonetheless refuses to represent as ‘victims’. One of the questions Bordowitz works through in Habit is: ‘how can people who exist across great divides of geography and resources have meaningful relationships? How can we join our efforts to address structural inequities implicit to global capitalism?’ Bordowitz demonstrates the concept of the echo and also does queer love as he attempts to bring into being just such a meaningful relationship across gaps of geography and resources.

In his essay, Bordowitz recalls being in South Africa at the Thirteenth International AIDS Conference in Durban in 2000, and feeling ‘nostalgia for the eighties activism of ACT UP’. Bordowitz describes his sense that he was reliving a moment from his past:

In Durban there were 5,000 people wearing t-shirts with the words ‘HIV positive’ boldly printed on their chests. I felt the urge to say, “Wow, this is
1989. This is just like 1989 was for us”. Of course, that is enormously arrogant and not correct. I had to think that through and I realized that the African situation is singular. It has its own integrity, its own logic. Undeniably, there is a shared history of activism around the world, and at the same time there are unassimilable differences between situations of crisis. In South Africa the well-informed core leadership of TAC [Treatment Action Campaign] has read Douglas Crimp’s work. It has followed ACT UP’s history. It has borrowed articulations and signage from all over the globe. Similarities were the first points of entry for me, but they do not yield the deepest understanding.81

New York City 1989 echoes forward in time to Durban 2000, but Durban 2000 is not a reproduction of the same, of that earlier time and place. The leaders of TAC read Crimp and know the history of ACT UP, but they transform that history and theory in a different time and place. How is it that ‘here’ might speak to ‘there’ across gaps of time and space? In Habit, Bordowitz proposes that ‘the reconciliation of habit and foreignness is intimacy,’ and the ‘substance of intimacy is love’.82 For Bordowitz, “[w]e can overcome great divisions through chosen affiliations’.83 In his presentation of the relationship between habit, foreignness, and intimacy in the video Habit and in the essay ‘More Operative Instructions’, Bordowitz demonstrates what I have been trying to describe here as doing queer love. Doing queer love is a method that asks, to paraphrase Foucault, ‘What relations, through health activism, can be established, invented, multiplied, and modulated?’ Doing queer love provides a model for overcoming great divisions through chosen affiliations, between lesbians and gay men, between AIDS activists in New York and South Africa, between the very precise moment of 1989 and the very precise moment of 2000.

Lisa Diedrich is Assistant Professor in the Women’s Studies Program at the State University of New York at Stony Brook. She is currently completing two book projects: the first, Treatments, analyzes contemporary memoirs on the experience of illness as both effective and affective histories; the second, Feminist Time against Nation Time, brings together essays that investigate how feminist voices challenge the emergency time of nationalism and war, and bring into being the time of feminism.
2. Ibid.
3. Ibid.
4. Ibid.
9. For a related analysis of how one figure may cover over the complexities of a social movement, see Victoria Hesford’s discussion of the feminist-as-lesbian figure in the second wave women’s movement in the article ‘Feminism and Its Ghosts’, Feminist Theory, 6:3, 2005, pp.227-250. For an analysis of competing cultural memories of AIDS activism, see Christopher Castiglia, ‘Sex Panics, Sex Publics, Sex Memories’, boundary 2, 27:2, 2000, pp.149-175.
11. Ibid. p.290.
12. Ibid. p.292.
15. Ibid. p.287.
17. Ibid. p.291.
18. In *The Body Multiple: Ontology in Medical Practice*, Durham: Duke University Press, 2002, Annemarie Mol argues that diseases are multiple objects that are enacted through a plethora of practices. She suggests that we investigate not how we know a particular disease, but how doctors, patients, nurses, caregivers, technicians, etc., do it. By focusing on how we do a particular disease, we might be better able to think through how we might do it better.


21. Ibid. p.335.
22. Ibid.
23. Ibid. p.336.
25. Ibid.
27. Ibid. This perhaps explains why the prospect of gay marriage is such a threat to many conservatives, who like to characterize the ‘gay lifestyle’ as hedonistic and irresponsible, and thus purportedly so radically unlike their own.
28. Ibid. p.137.
30. Foucault, ‘Friendship as a Way of Life’, p.139.
31. Virginia Woolf’s portrait of homosociality and homoeroticism among men in the professions in *Three Guineas* is revealing in this context. She describes the professional world from a woman’s perspective, which is also the perspective of the outsider, as one that ‘seen from this angle undoubtedly looks queer’. Virginia Woolf, *Three Guineas*, San Diego: Harcourt Brace Jovanovich, 1966 [1938], p.18.
32. Foucault, ‘Friendship as a Way of Life’, pp.139-140.
36. Ibid.
37. Ibid.
38. Ibid. p.5.
40. Ibid.
43. Ibid. p.120.
44. Ibid.
45. Ibid.
46. Ibid. p.122.
47. Ibid. p.123.
48. Ibid.
49. Ibid.
52. Ibid. p.124.
53. Ibid.
55. Interview with Gregg Bordowitz, ACT UP Oral History Project, A Program of MIX—The New York Lesbian and Gay Experimental Film Festival, 17 December, 2002. Transcripts and videos of these interviews are available online at http://www.actuporalhistory.org/.

57. Dreifus, Seizing Our Bodies, pp.xxv-xxv.
58. Ibid. p.xxviii.
59. Ibid. p.xxix.
62. Interview with Gregg Bordowitz, ACT UP Oral History Project.
63. Ibid.
64. Ibid.
66. Ibid.
69. Cvetkovich interviewed Schulman for her project, but interestingly doesn’t quote at all from that interview in An Archive of Feelings.
71. Ibid. p.194.
72. Ibid.
75. Ibid. p.38.
76. Ibid. p.39.
77. Ibid. p.270.
78. Ibid. p.273.
79. Ibid.
80. Ibid. p.274.
81. Ibid.
82. Ibid. p.275.
83. Ibid.