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Just Drop My Body on the Steps of the FDA: Emotion & Activism at ACT UP’s “Seize Control of the FDA” Action

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JUST DROP MY BODY ON THE STEPS OF THE FDA:
EMOTION & ACTIVISM AT ACT UP’S “SEIZE CONTROL OF
THE FDA” ACTION

by

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The outbreak of AIDS politicized and radicalized the gay community in New York City, which is when ACT UP emerged. The anger and hopelessness felt by the gay community due to the government’s inaction was vigorously channeled towards activism and disruption, which in turn created visibility and enabled changes that would make living with AIDS manageable. I will be focusing on the emotional aspect that drove ACT UP activists to channel their anger and frustration into something productive that ultimately lead to tangible changes. Changes related to how AIDS and people with AIDS were represented in the media and most importantly in terms of treatment availability. By looking at one particular action that ACT UP/NY was involved in, I hope to illustrate how the movement was inspired and driven by emotion, which in a lot ways made the movement more militant. Ultimately, we will see how the raw emotions and drive felt by a lot of the activists within ACT UP enabled them to become extremely interested in research and data gathering which opened the door for activists to become involved in the quest for new and fairer trials and treatments.
# Table of Contents

ABSTRACT ........................................................................................................................ iv

INTRODUCTION ................................................................................................................ 1

Chapter 1: Why the FDA or Why We Fight? ................................................................. 5

Chapter 2: SILENCE=DEATH .................................................................................... 20

Chapter 3: What Happens after you Seize Control ..................................................... 36

Conclusions ....................................................................................................................... 48
INTRODUCTION

While other scholars and authors have written about the history of ACT UP, with this work I want to analyze the link between emotion and activism. This thesis builds on the work of Deborah Gould who explores the emotional aspect of how ACT UP emerged and developed in her book, *Moving Politics*. Gould analyzes the role that emotion and affect played in a social movement like ACT UP. What I found very useful in Gould’s argument, which I also use on my second chapter, is her focus on how the plethora of emotions within the gay community sparked a movement that became incredibly effective in channeling different emotions people were feeling into action. I am taking Gould’s idea of analyzing emotion within ACT UP and scaling it down to one particular action. My goal is to hopefully explore how essential emotion was for ACT UP members, from interacting with one another and compartmentalizing themselves into groups to increase efficiency, to coming up with ideas for actions, to executing actions and finally how activists interacted with both the media and the public. By looking at one particular action, I can hopefully demonstrate more clearly all the nuances involved in planning an action for ACT UP from an emotional perspective.

When the AIDS epidemic broke out in the early 1980’s, little was known about the disease; what caused it, how to treat it and how to prevent it from spreading. Moreover, there was a lack of action and empathy in the hands of the government and health officials, leaving those suffering from AIDS to fend for themselves. It was on this environment that ACT UP emerged in late 1987; creating both a support system for those living with AIDS and creating a platform where they could express their anger and frustration towards how AIDS had been dealt with so far, and demand proper funding and action from the government.

Many of those who joined ACT UP NY, joined as a way to deal with their emotions, whether it’d be anger, sadness, or frustration, expressing themselves politically became a way for them to deal with their emotions.\textsuperscript{2} By looking at one particular action that ACT UP NY was involved in, both in planning and executing, I would like to show how emotion became a key factor in what made ACT UP so effective as an activist group, and how this played on the media.

Because the “Seize Control of the FDA” action was the first national action ACT UP NY took part in, and the biggest so far, it allows us to analyze several aspects of how ACT UP activists worked.\textsuperscript{3} Emotions like frustration and anger for how ineffective the FDA had been in dealing with the AIDS epidemic were driving forces as to why they chose the FDA to begin with, and these feelings were also prominently expressed throughout the action.\textsuperscript{4}

One of the major concerns ACT UP New York dealt with from the beginning was that of providing treatment and drugs to those suffering from AIDS. The main reason why ACT UP decided to target the FDA was because they believed that the FDA was the link between the government private sector and the consumer.\textsuperscript{5} The FDA was also responsible for the approval process of different drugs and managing their release, which usually took years, so the FDA was an obvious target to ensure a rapid release of treatment options.

ACT UP also argued that people living with AIDS should have agency in “every level of decision-making concerning research for a treatment and a cure for our disease”.\textsuperscript{6} A big part of

\textsuperscript{2} Deborah Gould, \textit{Moving Politics}, p. 181.
\textsuperscript{5} Susan Okis, “AIDS Coalition Targets FDA For Demonstration”, The Washington Post, October 11, 1988, Folder 17, Box 13, ACT UP New York Records, Manuscripts and Archives Division, The New York Public Library (hereafter AU-NYPL)
\textsuperscript{6} Gregg Bordowitz, “ACT UP Oral History Project”, Interview.
ACT UP’s argument was how important it was for those living with AIDS to be both involved and informed of treatment options.\(^7\)

ACT UP wanted to fast track the approval process of drugs currently being tested under the FDA, it was vital to create faster approaches and methods to get drugs tested and released in a safe way. The major question at hand was whether seriously ill patients should have access to experimental drugs as a form of treatment, and for ACT UP members the use of experimental drugs was healthcare.\(^8\) Drugs that were currently being tested (over 80 AIDS related drugs) were only available to those currently enrolled in the studies, while the rest of the population living with AIDS were left with no treatment.\(^9\) Vito Russo, from ACT UP NY, summarized their argument best by stating “The side effect of AIDS is death. I would rather take my chances with the side effects of drugs”.\(^10\)

Just prior to the FDA action on Monday the 10th, ACT UP staged a rally at the Headquarters of Health and Human Service Department, organized to look like a mock trial to ridicule Reagan’s administration.\(^11\) Speakers took turns to read charges against the administration while the crowd chanted “Guilty, guilty, guilty”. Their aim with this action was to bring light to the lack of action the administration had taken, especially the lack of funding the administration had allocated to AIDS research.\(^12\)

But the main event was to happen on early Tuesday morning, October 11th. Thousands of protestors arrived at the Food and Drug Administration Headquarters in Rockville, MD just

\(^7\) Ibid.
\(^8\) Robert Massa, “Acting Up at the FDA”, The Voice, October 18, 1988, Folder 17, Box 13, AU-NYPL.
\(^9\) Susan Okis, “AIDS Coalition Targets FDA For Demonstration”, The Washington Post, October 11, 1988, Folder 17, Box 13, AU-NYPL.
\(^10\) Front Page, “175 arrested in protest of FDA policy on AIDS”, The Houston Chronicle, October 12, 1988, Folder 17, Box 13, AU-NYPL.
\(^11\) ND, “Protesters Block FDA Office”, The Miami Herald, October 12, 1988, Folder 17, Box 13, AU-NYPL.
\(^12\) Renee Loth, “AIDS Activist’s put on “trial” for Reagan response to epidemic”, The Boston Globe, October 11, 1988, Folder 17, Box 13, AU-NYPL.
before 7:30am. The aim of the action was to effectively shut down and disrupt “business as usual” while addressing their demands.\textsuperscript{13} The protestors blocked the entrance to the 17-story building to thousands of employees who didn’t manage to get there early enough to avoid the protestors.\textsuperscript{14}

Demonstrators blocked traffic, smashed wooden police barriers, climbed unto doorways, plastered windows with anti-AIDS stickers and burned President Reagan in effigy.\textsuperscript{15} In one of the most dramatic moments of the protest, one of the demonstrators managed to drape a black banner reading “SILENCE=DEATH” above the FDA’s main entrance.\textsuperscript{16} The protesters were met by the Montgomery County Police force, locked arm in arm attired in riot gear and wearing latex or rubber gloves to protect themselves from infection.\textsuperscript{17}

The demonstration was organized so that they could garner the most media coverage, with the original goal of having at least 300 of participants arrested. While only 176 people were arrested, ACT UP’s well-organized action managed to successfully “Seize the FDA”; hundreds of FDA employees were unable to go to work, and many of those inside the building were glued to their windows to watch the action ensue, making work impossible.\textsuperscript{18}

People from all over the country gathered to protest the FDA, some wearing eye catching and controversial costumes to assure the media would pay attention; one group donned white lab coats splattered with red paint carrying a sign that said “The government has blood on their hands”.\textsuperscript{19} Some laid on the ground with signs reading “I died for the sins of the FDA” or “I got the

\begin{footnotes}
\item[14] FDA employees had been informed, weeks prior, of the need to arrive early on that day because of the protest.
\item[15] Renee Loth, “AIDS Activist’s put on “trial” for Reagan response to epidemic”, The Boston Globe, October 11, 1988, Folder 17, Box 13, AU- NYPL.
\item[16] Stephen M. Hagey, “Hundreds of protesters block FDA, charge inaction on AIDS treatment”, The Sun, October 12, 1988, Folder 17, Box 13, AU- NYPL.
\item[17] Paul Duggan, “1000’s Swarm FDA’s Md Office to Push Drug Approvals”, The Washington Post, October 12, 1988, Folder 17, Box 13, AU-NYPL.
\item[18] Renee Loth, “AIDS Protesters Shut Down FDA headquarters”, The Boston Globe, October 12, 1988, Folder 17, Box 13, AU- NYPL.
\item[19] Ibid.
\end{footnotes}
While the 9 hour action was at times loud and tense, it remained nonviolent, the only injury reported was an officer with a scraped nose.

While the “Seize Control of the FDA” Action was largely publicized and expected by both the media and the FDA, it nevertheless had a huge impact in terms of policy change and the way the media reported on AIDS. The FDA action represented a shift in terms of how activists were viewed, as some ACT UP members argued that actions like the one at the FDA were key in changing how those living with AIDS were represented.

Moreover, the FDA action was also a great example of how committed ACT UP activists were in using both non-violent techniques to garner attention, and also their use of theatrical elements to make their actions loud and memorable.

By looking at ACT UP NY through this one action, we can get a glimpse at the many elements within the group that made them so successful in planning zaps and actions that created the most media attention, and therefore, made it more likely for government and healthcare officials to work with activists and meet their demands.

Chapter 1: Why the FDA or Why We Fight?

By October 1988 ACT UP New York had been in operation for about a year and a half, gaining momentum with each action they organized. Furthermore, ACT UP branches had begun to pop up in different cities, according to ACT UP member David Barr these new ACT UPs just “sprung up around the country, sort of by, just by word of mouth”. They weren’t really organized with each other, or had any ongoing communication, and so the idea to do an action that would involve all the ACT UP branches made sense to everyone in ACT UP New York.

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21 Paul Duggan, “1000’s Swarm FDA’s Md Office to Push Drug Approvals”, The Washington Post, October 12, 1988, Folder 17, Box 13, AU-NYPL.
ACT UP members were also aware of how effective they could be when it came to their actions and how swiftly they could mobilize themselves once they recognized a potential target.\textsuperscript{23} The key to their successes was for them to work closely within their sub-committees in finding a target to protest and then organizing an action that would mobilize their entire membership, which would often involve hundreds of people;

“It was only when the people who were thinking on different issues came up with very particular targets that all of the membership…could get behind and put their bodies on the line for. That was the only time that ACT UP could actually make a change… there was a time when we had 400 people a week in the room, and we were able to affect change on several different fronts”.\textsuperscript{24}

In a pamphlet released to promote the “Seize The FDA” action, the reason why they chose to protest the FDA was stated as;

“We are demonstrating at the offices of the Food and Drug Administration because the FDA symbolizes the government’s inaction and negligence. We are convinced that agencies and statutes must change to create a more humane response to AIDS. The FDA, Congress and all other agencies must be held responsible in developing a coordinated, comprehensive plant to serve the people who suffer from AIDS”.\textsuperscript{25}

But of course, the action itself and how they came to choose the FDA as their target was a lot less simplified. It was not born just out of one meeting; but rather had to be presented on the floor at an ACT UP meeting, then to members of the other national branches of ACT UP, and then finally approved by ACT UP members.

\textsuperscript{24} Ibid.
\textsuperscript{25} ND, “Seize the FDA Action Pamphlet”, 1988, Folder 18, Box 13, AU-NYPL.
One of the main challenges, according to Jim Eigo, who was in the Treatment and Data committee, was to try to help those with AIDS financially with access to medical care; whether that was by trying to get them onto disability, Social Security, Medicaid and/or Medicare. Eigo, and soon the rest of the members of ACT UP begun to realize that being involved in healthcare, especially becoming involved with drug access and development had the “potential for doing the most people the most amount of good, in a quick, fast amount of time”.

The idea for the action was born out of a lunch between Treatment and Data Committee members; David Barr and Mickey Wheatley, and Gregg Bordowitz, who was part of the Action Committee within ACT UP. The Treatment and Data Committee was formed at around February 1988 and was primarily focused on data gathering and research. The idea of having a first national action was to gather the numbers to really make an impact that could have the potential to enact change. They all believed that it was time to organize an action that could include the numerous ACT UP groups across the country, with Bordowitz as point person, who was by then a well-recognized and popular figure within ACT UP. Because of the nature of the Treatment and Data Committee within ACT UP NY, they were already dealing with the FDA on issues of expanded access to drugs, which at this point in time, they felt was the key issue to deal with.

According to Bordowitz, the most essential part of the action was to “…cut through the bureaucratic red tape of the Food and Drug Administration…The action put us on the offense and enabled us to come with a vision for the way healthcare should be done in this country, the way

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27 Ibid.
28 Action Committee was focused in organizing the logistics of different actions and zaps.
29 While they had been operating under the previously formed Issues committee, they merged with David Kirschebaum’s, who was single handedly gathering a staggering amount of information.
drugs should be researched, and sold, and made available…most importantly…was the idea that people with AIDS should be at the center of the public discussion on AIDS”. So one of the main goals for Bordowitz and the rest of ACT UP was to make the rest of the public recognize the need there was to reform the healthcare system, to one that put the patient’s needs first and bureaucracy second. A member of ACT NOW, Urvashi Vaid argued that; “the FDA is at the nexus between the government, the private sector and the consumer. And that’s why we’re targeting them”. So in targeting an institution like that they were attempting to change how the FDA related to both the government and the public.

ACT UP wanted the FDA to speed up the approval process and to release the information of all drugs being tested, they wanted people with AIDS to have control of their decisions when choosing to take a drug. They knew the FDA had the power to legally change the approval process, and that is why they chose the FDA, because if they put enough pressure on them, the results would be tangible and potentially revolutionary.

Up until the time of the action, the number of options in terms of treatment for someone living with AIDS were extremely limited, basically the only drug available and approved was AZT. Part of the issue with AZT was to begin with, the cost, it was extremely expensive. In fact, AZT was the most expensive drug in history up until that time, costing up to US$10,000 a year.

33 ACT NOW was the coalition created to tackle the FDA national action, comprised of the numerous ACT UP groups across the country.
34 Susan Okie, “AIDS Coalition Targets FDA for Demonstration”, The Washington Post, October 11, 1988, Folder 5, Box 85, AU-NYPL.
36 ACT UP NY, “Seize Control of the FDA pamphlet”, ND 1988, Folder 5, Box 85, AU-NYPL.
though over 130 drugs had been approved as safe for human testing (Phase I of the FDA’s drug approval process), none of these were currently being tested through trials.38

The FDA was created as an organization to prevent useless and dangerous drugs to be released to the public, after the 1962 thalidomide scandal39, basically a middle man between the government, pharmaceutical companies and the public.40

The FDA set the standards for the approval process of all drugs, if their expectations were not met, a drug could not be legally released to the public.41 A lot of the drugs made available to treat AIDS were released via trials while still in the experimental phase, and the FDA was the regulating agent which decided what kind of criteria had to be met in order for patients to take part in these trials and have access to these experimental drugs.42

For a drug to be approved by the FDA, they had to go through three phases, a process that often took about seven years to complete43. The other way a drug could be approved in a swifter manner was if it fell under the Orphan Drug Act44, which was developed in April 1983, though not in response to AIDS, “to encourage the development and manufacture of drugs that treat diseases which affect so few people that the cost of developing the drug outweighs the potential profits”.45 The goal of the Orphan Drug Act was to locate potential orphan drugs and entice drug companies into developing them. The FDA in return would be more lax about testing criteria, which would enable a faster approval process, whilst also providing grants to fund

38 ACT UP NY, “SILENCE=DEATH Pamphlet”, ND 1988, Folder 5, Box 85, AU-NYPL.
39 Thalidomide, when used on pregnant women causes serious birth defects, a fact that was not released when being taken. Over 10,000 babies were born with some kind of defect as a cause of thalidomide use. – FDA HANDBOOK, ACT UP NY
40 Donna Minkowitz and John Soeder, “Why AIDS Activists Target the FDA”, The Village Voice, October 18, 1988, Folder 5, Box 85, AU-NYPL.
41 Ibid.
42 Jim Eigo, Mark Harrington, Iris Long, Margaret McCarthy, Stephen Spinella, Rick Sugden, “FDA Action Handbook” ND 1988, Folder 5, Box 85, AU-NYPL.
44 The Act was pushed by The National Organization of Rare Disorders (1982) as a way to create financial incentives for the development of treatments for rare diseases.
45 ND, “FDA Action Handbook” ND 1988, Folder 5, Box 85, AU-NYPL.
necessary research.\textsuperscript{46} Moreover, the cost of clinical trials could be partially claimed as a tax credit, in addition to granting the manufacturer with up to 7 years of exclusivity to the drug.\textsuperscript{47}

The issue ACT UP activists had with the Orphan Drug Act was that because of patent exclusivity, price gouging became an issue that the FDA had not addressed since the drug companies were not required to release any information regarding drug cost. The reason why this mattered to ACT UP activists was the fact that numerous AIDS related drugs currently being tested fell under the Orphan Drug Act umbrella.\textsuperscript{48} ACT UP members demanded that drug companies justify their exorbitant prices by releasing their books and justify their prices.

Outside of AZT and clinical trials, the only other way for a person with AIDS to access treatments was through two programs run by the FDA; Treatment IND (Investigational New Drug) and Compassionate Use IND.

Treatment IND drugs would be released for people with illnesses that have no known cure. In order for a drug to be available via Treatment IND, the drug company had to apply for that status and had to show that it was currently pursuing approval for the drug in question. The issue at hand was that not enough drug companies were applying to be included in Treatment IND because in order to apply they would have to open the books to justify their costs, since neither Medicaid or any insurance would cover a drug not yet approved by the FDA. Their demands here are focused on the FDA pressuring drug companies to apply by releasing drug names that would fall under this category, introduce or back-up laws that would require private insurance and Medicaid to cover these experimental drugs, and finally to consider all HIV related illnesses as life threatening.\textsuperscript{49} Drug approval was key for ACT UP activists because it meant that those unable to pay for treatment otherwise, would be able to access the drugs through Medicaid or insurance

\textsuperscript{46} Ibid.
\textsuperscript{47} Ibid.
\textsuperscript{48} Ibid.
\textsuperscript{49} ND, “FDA Action Handbook” ND 1988, Folder 5, Box 85, AU-NYPL.
once they had been approved. Under Treatment IND, once a drug had been approved, costs such as lab tests and doctor visits could be covered through Medicaid or insurance.\textsuperscript{50}

The second way a drug currently under investigational stages could be released was under Compassionate Use IND, which was used under two circumstances; either if the drug was proved effective to treat a particular rare disease but drug companies weren’t willing to invest in it if the returns weren’t worth it. This applied to drugs like Pentamidine\textsuperscript{51}, which before the AIDS epidemic was a drug with a very small market meant to treat a very rare disease. Under Compassionate Use IND these kinds of drugs would then be allocated to be released to AIDS patients.

If a drug was currently under experimental processes but might be useful against a particular illness, then it would also fall unto Compassionate Use IND.\textsuperscript{52} The issue with the experimental drugs that fell under this category, which were almost all the AIDS drugs currently being tested, was the complicated process requested by the FDA. A doctor had to fill in paperwork regarding a patient applying for a particular drug, and then the FDA would review the file and see if it could be released, a process that often took weeks. When it comes to a disease like AIDS, waiting weeks for a chance of treatment was the difference between life and death.\textsuperscript{53}

It is important to emphasize that one of the slogans used by ACT UP for the FDA action was the notion that healthcare is a human right, and in this case experimental drugs were healthcare.\textsuperscript{54} Because of the limited treatment options for people with AIDS, the opportunity to take part in experimental clinical trials were often the only choice available once using AZT was not an option\textsuperscript{55}.

\textsuperscript{50} Ibid.
\textsuperscript{51} Used to treat PCP, or Pneumocystis Pneumonia, a very common opportunistic infection in people with HIV.
\textsuperscript{52} ND, “FDA Action Handbook” ND 1988, Folder 5, Box 85, AU-NYPL.
\textsuperscript{53} Jim Eigo, “ACT UP Oral History Project”, Interview.
\textsuperscript{54} Ibid.
\textsuperscript{55} AZT was the only known drug at the time approved by the FDA to treat AIDS.
There were numerous issues activists had with the way the FDA was running experimental trials. To begin with there was an obvious lack of diversity in these trials, inclusion of a wide selection of people was imperative in terms of making sure access to treatment was available for all. Activists had begun to realize that most subjects currently enrolled on the major drug trials were well educated white gay men living in major urban areas. This did not represent the scope of people being affected by AIDS seeing as how these trials regularly excluded women, IV drug users, hemophiliacs, children and people of color. 56

In addition to demanding more diversity in experimental trials, ACT UP activists wanted the FDA to ban the use of placebos since it would rob the person enrolled in the trial of any kind of treatment, death as an endpoint for a clinical trial was considered inhumane. Activists argued that the use of active controls (maybe against a drug proven effective like AZT) would be a more humane approach to gathering data. The need for some kind of treatment should trump the need to carry out experimental drug trials in a particular way. 57

Finally, ACT UP activists wanted to make sure that new trials being conducted would be properly listed and advertised; “the FDA must provide a comprehensive, accurate, timely registry of all AIDS drug trials...both private and public ones. 58 Moreover, they argued the information and data gathered through these experimental trials be made available to those involved and their doctors. One of the main ACT UP members in charge of research, Iris Long, was already aware about the lack of information regarding medical trials, whether that pertained to where they were being held or what kind of requirements they needed; “The hospitals do not- or, the doctors do not get information about clinical trials out to people...You couldn’t give medical information, if

56 ND, “FDA Action Handbook” ND 1988, Folder 5, Box 85, AU-NYPL.
57 ND, “Seize the FDA Action Pamphlet”, ND 1988, Folder 18, Box 13, AU-NYPL.
58 ND, “FDA Action Handbook” ND 1988, Folder 5, Box 85, AU-NYPL.
you weren’t a doctor”.59

Once the idea to protest the FDA was presented to the other ACT UP NY members at one of their weekly meetings, and swiftly approved, they proceeded to set up a meeting with the other ACT UP chapters across the country in San Francisco where it was also approved.60 The next step was to organize their first national action successfully.

The demonstration at the FDA proved to be pivotal in how ACT UP NY was structured as well. For instance, the affinity group structure within ACT UP really solidified itself during the planning for the action. A lot of the affinity groups within ACT UP were first created for this action, while others like the Media committee or the Treatment and Data committee consolidated their relevance by showing how effective they were at both gathering research, planning and, developing and publishing useful material.61

Because the FDA action was until that point the largest action ACT UP had planned, a lot of different logistics they had never dealt with before had to be taken into consideration. It was the first time ACT UP members were going to be transporting people to and from different cities, and this required a certain level of organization they had never experienced, such as signing people up for buses, figuring out housing and accommodations and also coming up with funding62. In order to make sure basic needs like transportation and housing were secured, new committees started to appear, some for the sole purpose of the FDA action, like the FDA Transportation Committee.63 The idea of affinity groups came out of the work activists had been doing in the 60’s, ACT UP NY member, Jim Fourrat argued that what was appealing about this kind of structure

60 David Barr, “ACT UP Oral History Project”, Interview.
63 ND, “Seize the FDA Action Pamphlet”, ND 1988, Folder 18, Box 13, AU-NYPL.
was that “you didn’t have to believe in everything in ACT UP…. These are called cells. This is the old communist method…they’re called affinity groups…some people wanted to plan dances…some people wanted to talk politics and some people wanted to talk about being latin…”64 And this is why the committee strategy worked so well for ACT UP, because they could assign different committees with different tasks, and different inclinations without having the need for a centralized leadership;

“We kind of adopted the kind of brilliant strategy of the decentralized model, the affinity group model. So, affinity groups could do anything they wanted, within parameters.”65

A lot of the earlier stages of planning for the action were centered around educating the ACT UP membership as to why they were targeting the FDA and to understand what the issues at hand were. While several people within ACT UP were already well versed and informed, and in turn were doing teach-ins to educate the rest, there was a language barrier when it came to talking about very advanced scientific issues. Mark Harrington, who also participated in the Treatment and Data committee, quickly detected how scientific language could alienate some of their members;

“The first issue…was that the language that was being used…needed to be explained to the rest of ACT UP. And the very first thing I did was, I went to their teach-in66, and I just wrote down every word that I didn’t understand… and made a glossary out of it, and distributed to ACT UP in July…I felt it was very important for the FDA demo to be a success for people to understand what the issues were.”67

So, on the one hand, ACT UP activists argued the need to engage their membership with

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66 The Treatment and Data teach-in
scientific language they had not been exposed to before, and get them to comprehend the issues. On the other hand, activists argued that there was also a need to educate each other on who the FDA were and were they stood in in relation to drug laws and regulations; meaning they needed to locate the issues they were protesting in terms of how protesting the FDA would bring them closer to their goals. Because it was the largest action they had tried, it was seen as essential for ACT UP members to understand, so that when it came time to demonstrate, “they could get the message across the American people”.

Together with the Media Committee, Treatment and Data also helped further educate those who were going to be spokespeople for the group, so that they could present themselves in an articulate and clear manner to the media when being interviewed on TV or during a radio show.

While attending the teach-ins was not a requirement in order to participate in the action, ACT UP did encourage its members to attend. ACT UP held numerous teach-ins regarding the FDA and its policies months before the action, with varied schedules to ensure maximum participation.

Another important aspect that ACT UP organizers had to deal with was preparing those participating in the action with “civil disobedience training”. ACT UP took a lot of inspiration from the Civil Rights movement, and non-violent direct action became part of their raison d’etre; “The strength of non-violence is our willingness to fight oppression without threatening others.” Part of this training involved working with people who had never taken part in civil disobedience before and showing them what to expect from that kind of experience and what basic principles they

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70 ND, “Knowledge=Power Pamphlet with teach-ins schedule”, ND 1988, Folder 18, Box 13, AU-NYPL.
71 ND, “Seize the FDA Action Pamphlet”, 1988, Folder 18, Box 13, AU-NYPL.
should be following, especially when dealing with the police.\textsuperscript{72}

Many ACT UP members, even those who had been politically active beforehand, had never been involved in a group or organization that required that level of preparedness. Civil disobedience training for them was both a foreign concept albeit a useful one, it also meant learning about what it meant to engage in civil disobedience.\textsuperscript{73}

Several of the ACT UP members came from political backgrounds, a fact that will be explored further in the next chapter, and had had experience when it came to civil disobedience, like Amy Bauer, who was one of the many people in charge of CD training;

“In the group, we talked...about people being responsible for their actions, about not running, not throwing things. And just things that you can do to try to keep people from panicking, about sitting down to diffuse potentially violent situations... And constantly talking about things like that I think really made a difference in the way we were able- the cohesion we had at our demonstrations.”\textsuperscript{74}

ACT UP members encouraged those participating in the action coming from outside New York to participate in non-violence training within their communities prior to the action, as non-violent direct action was the coalition’s foundation from the beginning, since a lot of the inspiration they drew on was based on the Civil Rights movement.\textsuperscript{75} In addition to the numerous teach-ins held beforehand, on the day prior to the FDA action, ACT UP NY, mostly led my members of the

\textsuperscript{75} Gregg Bordowitz, “ACT UP Oral History Project”, Interview.
Action committee, held a non-violent training to ensure everyone involved would be prepared.\textsuperscript{76}

Going through civil disobedience training prepared those involved in the action with potentially tense situations, and because more arrests meant more press, there was a consensus going into the action that there would be “sort of an arrest”.\textsuperscript{77} At the same time, activists did not want to alienate those that supported the cause yet they did not want to be involved in arrests or controversy, in one of the flyers advertising the FDA action they explicitly state “You may participate without planning to be arrested.”\textsuperscript{78} It was all about inclusion and making sure they would not be alienating potential allies.

The Media committee meanwhile, was to be in charge of publicizing the event to the media, to ensure maximum exposure, and to also prepare other ACT UP members to deal with the press. Given the size of the action, and the fact that it included other ACT UP branches, this was the biggest action the media committee had dealt with thus far.\textsuperscript{79}

Coincidentally, numerous of ACT UP members involved in the media committee had a significant amount of experience in the publicity industry; some dealt with entertainment, while some focused-on book publicity and some had experience covering protests and more political events. Those involved in the Media committee included Michelangelo Signorile, Jay Blotcher, Bob Rafsky, Jim Fourrat and Vito Russo, some worked for newspapers, some had been involved in publicity, while some like Russo were part of the film industry. Moreover, they had the advantage of having supporters in many different cities, which gave them the idea to book them people on different local TV shows, radio shows, around the country and send out press kits to promote the action. Another sub-committee within the Media one, nicknamed the Little Publicists, since they would mostly follow up after the press kits had been sent, would then reach out to different TV and radio producers to make sure they had received the press kits and talk up the

\textsuperscript{76} ND, “Seize the FDA Action Pamphlet”, 1988, Folder 18, Box 13, AU-NYPL.
\textsuperscript{77} Russell Pritchard, “ACT UP Oral History Project”, Interview by Sarah Schulman, Interview.
\textsuperscript{78} ND, “ACT UP/ACT NOW FDA ACTION pamphlet”, 1988, Folder 18, Box 13, AU-NYPL.
\textsuperscript{79} Michelangelo Signorile, “ACT UP Oral History Project”, Interview.
“...The Little Publicists would call them up and say, “Did you get our press kit? There’s this huge action coming. It’s going to be huge news- the largest thing since the storming of the Pentagon”...So, it was all that kind of sophisticated hype machine of you know we’re going to tell them it’s going to be big and they’re going to then make it big.”⁸⁰

It did not matter that ACT UP didn’t quite have the numbers to make it the biggest protests since the Pentagon, by promoting themselves as such, they were making sure that the media would be listening. Furthermore, a lot of work went into pre-publicity work, their target was to capture the attention of middle-America, and by talking about families torn apart by AIDS, sons, daughters, fathers, ACT UP tapped into the compassion of the audience (the American public watching); “In addition to getting visibility for people with AIDS- doing this was also going to force all the newspapers and the TV in those markets to have to cover the demonstration when it happened.”⁸¹ The visibility also helped empower local activists to engage and promote the action separately, garnering the FDA action with an extra dose of publicity.

To ensure the action would make the front page on newspapers around the country, the Media committee came up with a plan with the help of Urvashi Vaid⁸². Because they had activists from around the country, they would announce to reporters, whether from TV or newspapers, where to find people from the cities they were reporting to on the day of the action, therefore making their stories more personal to their particular audiences. Michelangelo Signorile, who was working in the Media Committee, argued “that made the difference between the protests getting page five in the Arizona paper, or the Dallas *Morning News*, and being on the front page, because there was a local person there.”⁸³

They used the same tactic with radio producers, by having local people from different

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⁸¹ Ibid.
⁸² She was at that time handling PR for the National Gay and Lesbian Task Force.
cities, radio shows would be much more likely to cover the protest live as well. The whole tactic that ACT UP members were trying to work with was the idea of working with the press rather than against them, making sure they had a good line of communication and giving them as much information as possible. This applied not just to this particular action but throughout their active years, making themselves visible and relevant by showing how diverse and “normal” they were, therefore reaching the American population.84

Bordowitz looks back on the kind of media attention they were getting at the time of the FDA action as crucial; “…we shifted the ground and wrested the discussion on AIDS out of the hand of the right wing. All of a sudden, we had people from the group representing people with AIDS in the conversation.”85 Given that one of the goals of the FDA action was to seize control, to give those with AIDS the power to decide and have a say in their treatments, the fact that they could finally take control of the narrative of AIDS and how they were represented and viewed by others was essential.

Chapter 2: SILENCE=DEATH

The Seize the FDA Action was part of a four-day civil disobedience event sponsored by ACT NOW\(^{86}\). Part of the events included an “AIDS Activism: A Teach-In” on the first day, a meeting of ACT NOW members to discuss the possibility of future collaborations the following day and on October 10\(^{th}\) a rally was held at the Department of Health and Human Services. All these events served as a countdown of events, culminating on the FDA action on October 11\(^{th}\).\(^{87}\)

The rally held the afternoon of October 10\(^{th}\), just prior the FDA action, at the Department of Health and Human Services (HHS) was planned to ensure maximum media coverage, a way to guarantee the gathering would be widely publicized which in a way also helped build anticipation for the FDA action the following day.\(^{88}\) The HHS rally was centered around similar demands to those targeted at the FDA, mainly to increase funding for AIDS research, distribute AZT to anyone that required it regardless of coverage, and to guarantee more fair and accelerated AIDS drug trials.\(^{89}\)

The rally at the steps of the HHS in Washington was organized to look like a mock trial against the Reagan administration, a self-described “courtroom dramedy”, which included drag characters and a judge reading “charges” against those being tried and on each account read, cries from the crowd would respond with “guilty, guilty, guilty”.\(^{90}\)

One of the most emotional moments of the HHS rally happened when Vito Russo took the stand and delivered his now famous “Why We Fight” speech. Russo’s speech is important

\(^{86}\) ACT NOW was the coalition of the different ACT UP contingencies around the country, it stood for AIDS Coalition to Organize and Win.
\(^{87}\) Bernard Weinraub, “AIDS Activists Take Control”, The Guardian, October 12, 1988, Folder 1, Box 14, AU-NYPL.
\(^{88}\) ND, “Turn the Power of the Quilt Into Action – ACT NOW pamphlet”, October, 1988, Folder 17, Box 13, AU-NYPL.
\(^{89}\) ND, “ACT NOW ’88 Handbook”, October 1988, Folder 17, Box 13, AU-NYPL.
\(^{90}\) ND, “Protesters Block FDA Office”, The Miami Herald, October 12, 1988, Folder 17, Box 13, AU-NYPL.
because first, it ties in with the events that took place at the FDA, but most significantly, it manages
to symbolize the same feelings of anger and frustration that drove many activists to join ACT UP
and become politicized.

Russo started his speech by stating “I’m here to speak out today as a PWA who is not
dying from- but for the last three years quite successfully living with- AIDS.”91 The importance of
Russo’s speech lies in the fact that it emphasized the willingness to fight against the government’s
idleness, the fact that those living with AIDS refused to see themselves as victims and were
instead in the frontline of the movement.

He continues to talk about the portrayal of those living with AIDS; “If I’m dying from
anything it’s the sensationalism of newspapers and magazines and televisions shows that are
interested in me as a human-interest story only as long as I’m willing to be a helpless victim, but
not if I’m fighting for my life. If I’m dying from anything it’s the fact that not enough rich, white,
heterosexual men have gotten AIDS for anyone to give a shit.”92 This sentence encapsulates the
importance of media representation, both for activists themselves and for those consuming the
media. Russo wants to emphasize that they are not just some sad story mean to be consumed
as entertainment, and they will not accept being portrayed as such when they are obviously
putting up a fight.

Russo’s speech also addressed the fact that it was the government’s irresponsibility and
lack of action that was killing those living with AIDS. He and others with the disease were dying
from homophobia, from racism, from indifference and red tape, from Jesse Helms and Reagan.93
He continued; “They94 don’t spend nights and months and years trying to figure out how to get the
latest experimental drug, and which dose to take it at, in which combination with what other drugs

91 Vito Russo, “Why We Fight”, October 10, 1988, Folder 17, Box 13, AU-NYPL.
92 Ibid.
93 Ibid.
94 Referring to the government and media.
and for how much money... They don’t spend their waking hours going from one hospital to another, watching the people they love die slowly of neglect and bigotry- because it isn’t happening to them. They haven’t been to two funerals a week, so they don’t give a shit. In this sentence we can really see how the anger and frustration felt by Russo has inspired him to become active, it’s extremely personal for him and this is his whole argument, the fact that nobody cares because it isn’t personal to them. Most of ACT UP members, both those living with and without AIDS, could relate to Russo’s words; they too had to research and guess where to find treatment and drugs, they too had to care for sick friends and lovers, they too had to bury their loved ones, while the rest of the world looked on, doing nothing.

Russo continued his speech by talking about the importance of being an activist in the current crisis; “Remember that someday the AIDS crisis will be over. And when the day has come and gone there will be people alive- gay and straight people, black and white people, men and women- who will hear that once there was a terrible disease, and that a brave group of people stood up and fought and in some cases died so others might live and be free. I’m proud to be out here today with the people I love, to see the faces of those who are fighting this war, and to be a part of that fight. And after we kick the shit out of this disease I intend to be alive to kick the shit out of this system so that it will never happen again.”

After the speech, when asked why he was protesting, Russo replied; “I’m here because I want to live. I don’t want a quilt with my name on it to be in front of the White House next year”. Activists were literally fighting for their lives, channeling every emotion of anger, sadness and regret in their bodies towards those responsible.

For many ACT UP members, joining the organization became a way to channel the helplessness and anger they felt, especially when confronted with the idleness of the government

95 Vito Russo, “Why We Fight”, October 10, 1988, Folder 17, Box 13, AU-NYPL.
96 Ibid.
97 ND, “175 seized at the FDA in protest on AIDS drug”, The Chicago Sun Times, October 12, 1988, Folder 1, Box 14, AU-NYPL.
when it came to dealing with AIDS. Using mostly ACT UP’s Oral History Project interviews I will try to analyze how members dealt with their emotions, and how through becoming a member of ACT UP they learned to channel these emotions and turn their sadness into rage and anger towards the government and health officials.

I will first try to illustrate the significant role that emotion played in the lives of ACT UP members and then how this related to a desire to become active and militant in the movement, so trying to link emotion to the growth of ACT UP as a movement by linking it to the FDA action, which was their biggest action yet. In other words, trying to analyze the link between ACT UP members’ use of emotion and especially anger to drive themselves into action, and how this engaged them creatively into how they expressed themselves at the FDA specifically.

On the one hand, people were working on turning their grief and anger into action, on the other however, there was also a sense of not understanding the lack of empathy and the silence surrounding AIDS, why no one else was addressing the issue and how they could work towards forcing the issue on those being silent.98 Mark Harrington, who was in the Media and, Treatment and Data committee of ACT UP/NY was generally angry about the general population’s passivity regarding everything AIDS related; “…I didn’t really know what ACT UP could do, but it seemed to me like the only possible first reaction would be to do something like ACT UP.”99

Silence became a huge symbol for ACT UP, the poster “SILENCE-DEATH”, created by Gran Fury art collective member Avram Finkelstein with other artist friends, became synonymous of ACT UP. When discussing how the idea of the poster came about, Finkelstein remembers being heavily influence by his political upbringing and his living surroundings; “I have a deep history with the political poster. Sometimes I feel like I was raised with a political poster in my

hand... Eighth Street was literally papered with posters, manifestos and diatribes. It was literally like a billboard...and I remember that as a very vital way that people communicated in the street. It was free.”100 Finkelstein says that they wanted to both rally the lesbian and gay community politically, and seem threatening to those outside of the community, they wanted to give the idea that they were much more organized as a community than what they actually were.

Finkelstein suggested the idea to the group of coming up with a poster that would express the frustrations of living through the AIDS crisis as part of a bigger campaign while still remaining anonymous. While a lot of ideas were discussed they decided it would be a better idea to keep it simple, since they would be competing for the public’s attention, it had to be eye catching; “So it was going to go alongside the commercial posters of the day, and that was our decision, that it would be big, it would be glossy, it would complete in that visual context.”101 The decision to choose a black background was born out of the need to define the space the poster was going to be placed in, to neutralize it. The idea of the pink triangle wasn’t initially welcomed because it historically symbolized victimhood for the gay community, but by redesigning it, by inverting the pink triangle they wanted to reclaim the symbol as a “gesture towards action, not passivity”102, trying to distance themselves from victimhood.

The text that came with the poster was meant to engage those looking at it, challenging you to think about the claim being posed; “It was very much Gran Fury’s strategy as well, to not tell you what to think, to lead you there...the best way, the only way to draw somebody who only peripherally saw the poster would be for it to be mystical, threatening, hostile, provocative, interesting, intriguing, and that's how we came up with the text, “Silence= Death.”103 ACT UP used the poster to promote itself as a group, and it soon became a symbol of the group, even

100 Avram Finkelstein, “ACT UP Oral History Project”, Interview.
101 Ibid.
103 Ibid.
though the poster, as well as Gran Fury, were created independently of ACT UP.\textsuperscript{104} Nevertheless it managed to express a lot of the feelings towards inaction and apathy at the hands of the government and public that were felt by ACT UP members.

Moreover, ACT UP combined the draw of being a community where one could be both political and social\textsuperscript{105}, ACT UP/NY member Maxine Wolfe describes the experience of being in ACT UP as a “combination of serious politics and joyful living”.\textsuperscript{106} Being part of ACT UP gave Wolfe a sense of belonging; “We would go and do actions where we really put our bodies on the line, and then we’d go out an party all night…If you don’t have a community, if you don’t have a way of being, of people that you can be with, who make you feel good about who you are…you’re not going to stay in it.”\textsuperscript{107}

Along the same lines as Wolfe, ACT UP/NY member David Barr also felt attracted to ACT UP because he felt like he finally belonged; “I liked the energy in the room and I liked the approach…There were all these really cute guys and they were interesting and they were political and I had just never seen anything like it before. I thought, ‘Finally. I’ve been looking for this all my life’. I really felt like I was home.”\textsuperscript{108}

In addition to providing its’ participants with a sense of community, there was also a draw that came from the militancy, the legacy of gay activism, that ACT UP represented.\textsuperscript{109} For ACT UP/NY member Kendall Thomas, it was his experience with gay activism in the 1970’s that gave him the groundwork to understand sexuality “…to be both a ground of political action and a tool

\textsuperscript{104} Ibid.
\textsuperscript{105} Gould, \textit{Moving Politics}, 183.
\textsuperscript{107} Ibid.
\textsuperscript{108} David Barr, “ACT UP Oral History Project”, Interview.
that could be mobilized to organize other people politically.”\textsuperscript{110} He argues that there was a shared identity amongst those within ACT UP, even before the AIDS crisis, that placed them in a particular position in history where things like pleasure and sex could be articulated as a political issue; “Gay men and lesbians...[became] the agents in American culture of a project of social and cultural change, in which something like the right to pleasure might be taken seriously...The conditions of possibility for collective, political action, of the kind that ACT UP undertook- and in understanding specifically of culture as both an arena and an instrument for political struggle – those things would not have been possible, if people hadn’t shared this experience.”\textsuperscript{111}

Many saw ACT UP as the only organization capable of helping them channel their anger and grief into something useful, ACT UP/NY member Maria Maggenti always felt the need to be a part of something meaningful and “…the understanding was that you would take your grief and you would turn it into rage, and you take that rage and you would do something with it...A lot of people felt that (sadness, grief) and did not want to feel those things, and were tired of feeling sad and alone and defeated.”\textsuperscript{112}

It was a way for many to find an outlet to their emotions, similarly to Maggenti, Peter Staley also felt a lot of anger building up inside of him with the only outlet being to become politically involved; “…I was building up a lot of anger and I really felt that the way this was going to break politically was the expression of that anger in a very activist way.”\textsuperscript{113}

Gregg Bordowitz was also attracted to the militancy, anger and especially intensity that was associated with ACT UP; “ACT UP was everything. ACT UP was home...The meetings were just packed. You had to touch a hundred bodies to get across the room, it was a very erotically

\textsuperscript{110} Ibid.
\textsuperscript{111} Ibid.
\textsuperscript{113} Peter Staley, “ACT UP Oral History Project”, Interview.
charged place to be. And that was part of it. I was into it. I was into that kind of politics. I had heard about revolutionary joy but here was my time to experience it…. It was lifesaving. It was a place to go to get support. It was a place to put all my energies into…There were a lot of people who were throwing all of their energy into ACT UP, like nothing else mattered… I don't remember anything except going to meetings and actions during that time.”

The aspect of belonging and throwing yourself and your energies into something bigger was a big draw for a lot of ACT UP members because so many of them had lost friends, lovers and family to the disease. So, for many activists, ACT UP and activism in general, became a way to identify the feelings of sadness and frustration, and turn them into anger and rage. Being part of ACT UP meant being angry, angry at the government for its lack of action, angry at health officials for not caring enough, and angry at those outside of the community, for not caring they were dying.

Vito Russo, was a film historian and critic and an active member of ACT UP/NY and talked about becoming an AIDS activist in the context of immense loss. In an interview in the Winter of 1988, when asked if it was the loss of loved ones that propelled him into taking a more prominent activist role, Russo replies; “Yeah, it has…It's not natural at this age (42) for me to have lost most of the people I love. And so you throw yourself into politics…. [ACT UP] became a whole new phase of activism, not only for me, but for the community in general. And it's a new kind of activism, because it’s created a coalition, which we were never able to achieve in the '70's... There always have been and there will always be people who are willing to put their lives on the line for those ideas.”

When discussing the importance of being involved in AIDS activism, ACT UP/NY member Marion Banzhaf who was also a longtime activist, differentiated ACT UP from her previous political

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114 Gould, Moving Politics, 184.
116 Ibid.
work; “It was…the most exciting political work I’ve done in my life, without a doubt. And it was also the most immediate. Lives were definitely on the line… I think there was- there was such an urgency about fighting for lives, that people were really alive, and living everyday as though It might be their last, because in fact, it really might be.”\textsuperscript{117} So the sense of urgency within the community, the knowledge of how ACT UP’s work was perceived by some as the difference between life and death was another way in which feelings of loss and anger were tied together.

There was also a sense of comradery during ACT UP meetings, where people of different ages, backgrounds, ethnicities, were all politically united by a sense of urgency. Participants felt encouraged by each other to be angry at the state and society for neglecting to address their issues, and being part of a group that reflected both their views and feelings in turn inspired many to be unapologetic in their activism.\textsuperscript{118}

ACT UP members started all of their meetings by stating that they “were united in anger and committed to direct action to end the AIDS crisis”,\textsuperscript{119} anger even became ACT UP’s calling card. Outsiders often viewed ACT UP as anger driven group, feeling almost threatened to the point of violence, but while ACT UP walked a fine line between anger and violence, it never crossed it\textsuperscript{120}. Moreover, the fact that ACT UP members often went “all out” on their protests, wearing their feelings on their sleeve, and being open about their anger earned them respect from the public, even if outsiders didn’t always agree with the message because it showed they were not going after their goals half-heartedly.\textsuperscript{121}

Michelangelo Signorile, who was in the media committee of ACT UP/NY talks about how ACT UP became a way in which people learned to channel their anger into something productive;

\textsuperscript{117} Marion Banzhaf, “ACT UP Oral History Project”, Interview by Sarah Schulman, Interview No. 070, April 18, 2007, New York Public Library transcript, \url{http://www.actuporalhistory.org/interviews/alpha.html}
\textsuperscript{118} Gould, \textit{Moving Politics}, 188.
\textsuperscript{119} Ibid, 188.
\textsuperscript{120} Michelangelo Signorile, “ACT UP Oral History Project”, Interview.
\textsuperscript{121} Ibid.
“I think in ACT UP, there was a lot of anger- at the government, at the media- for the way that the epidemic was being handled. And people’s personal lives were in turmoil, were turned upside down…. In a way, what the group provided was a way to channel that anger, in a way that helped to try to change things.”\textsuperscript{122}

For James Lyons, who was in ACT UP/NY, he felt the group gave him a feeling that being involved politically was crucial when it came to the AIDS crisis.\textsuperscript{123} Moreover, like many other members, he felt that being involved in it was almost like a way of mourning; “...I think mourning is classically defined as going through all these different patterns and of them is anger and anger was almost synonymous with ACT UP for a long time. And people forget that the anger wasn’t about not being paid attention to, the anger was about hundreds and hundreds of people dying and that’s not being paid attention to...that awful experience that the world was changing in this way and no one cared made me realize that I had to fight for myself and for my friends.”\textsuperscript{124}

In a lot of ways, it was also anger that attracted a lot of new members to join ACT UP, seeing the anger many felt being transformed into something effective was captivating to many. For ACT UP/NY member Jay Blotcher, it was seeing ACT UP in action that convinced him to join; “I’d been to a few things here and there, but, no, seeing these people in full force and full fury and full beauty…was just overwhelming…I liked the anger, the excitement, the eloquence of what they were doing. It got me.”\textsuperscript{125}

While ACT UP’s slogan was unofficially tied up with anger, it was also framed in terms of non-violence, a fact that not all members of ACT UP agreed with. ACT UP/NY member Rollerena believed that by framing their actions as non-violent their group would be regarded as weak, or

\textsuperscript{122} Ibid.
\textsuperscript{124} Ibid.
\textsuperscript{125} Jay Blotcher, “ACT UP Oral History Project”, Interview.
incapable of fighting back; “Why should I bend over backwards to inform my adversaries that im “non-violent”… I feel this ‘non-violent’ addition will make us look wimpy. If your lover dies of AIDS and your landlord violently evicts you, should you fight back or wimp out?…If we endorse non-violence then what’s the point in shouting our anger when they can say we are being violent with our mouths?...Are we going to drop our wrists, or raise our fists?”

Leading up to the FDA demonstration, the ACT UP media team acknowledged the fact that there were many strong emotions that drove their membership and used it in turn as a way to rally both support from new potential members and to encourage those already involved. This had already been done during the days leading up to the Washington march when the AIDS quilt was first displayed, in one of the pamphlets used to promote the march they stated in all caps “SHOW YOUR ANGER TO THE PEOPLE WHO HELPED MAKE THE QUILT POSSIBLE: THE GOVERNMENT.” Another ACT NOW pamphlet expressed the same sentiment by stating; “More than 40,000 people have died from AIDS. One person dies from AIDS every half hour. Before this Quilt grows any larger, turn your grief into anger. Turn anger into action.”

A way in which ACT UP members managed to make the FDA Action bigger than it was supposed to be was their media tactics, using the skills and drive of different members to create an emotionally charged protest. Engaging people’s anger and emotions into an electric atmosphere. Rumors circulating about what exactly was going to take place at the FDA headquarters also increased anticipation for the event, with some claiming protesters were “going to throw blood and urine.” The demonstrators met one last time before the FDA action on the

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126 Rollerena, “Note written on flight from Atlanta”, July 19, 1988, Folder 1, Box 14, AU-NYPL.
128 Bolded on original pamphlet
129 ND, “Washington March, Quilt project pamphlet”, Oct 1988, Folder 17, Box 13, AU-NYPL.
130 ND, “Turn the Power of the Quilt Into Action – ACT NOW pamphlet”, October, 1988, Folder 17, Box 13, AU-NYPL.
131 Dan Bellm, “STORMING THE FDA; A Power and Passion Play”, The Village Voice, October 25, 1988, Folder 1, Box 14, AU-NYPL.
the night of Monday 10th at the Church of All Souls to discuss what each affinity group was planning for the action.132

ACT UP/NY member David Barr remembers how in spite of the fact that there were ‘only’ a thousand people in the demonstration it looked much larger than what was seen on television.133 Barr credits the theatricals of the event as to why it seemed that much bigger than it was in reality, the demonstration and its many stunts and acts were described by reporters as being “as rehearsed and accessorized as any Royal Shakespeare production.”134

Signorile also agreed with Barr in that the visuals of the rallies and protests were key for promoting ACT UP’s actions; “One thing about ACT UP that kind of blunted that was that when there was a protests, because the signs and the theatrics and the costumes and everything else were so good, and so focused and so pointed, that no matter what the media did…the picture was there, and the message would get out…Even if the reporter was skewing the story, the visual was good.”135

Stephen Hagey from The Sun described the rally as “…at times, the protest yesterday seemed almost festive, with demonstrators clearly enjoying themselves as they tested the resolve of Montgomery County police officers.”136 Michael Musto from the Village Voice described the mood of protesters right before the FDA demonstration as being as “high as backstage before a high school sing…They hugged and kissed; very few stopped to cry.”137

132 Kiki Mason, “FDA: The Demo of the Year”, The New York Native, October 24, 1988. Folder 1, Box 14, AU-NYPL.
133 David Barr, “ACT UP Oral History Project”, Interview.
134 Michael Musto, “La Dolce column”, The Village Voice, October 25, 1988, Folder 1, Box 14, AU-NYPL.
136 Stephen M. Hagey, “Hundreds of protesters block FDA, charge inaction on AIDS treatment”, The Sun, October 12, 1988, Folder 17, Box 13, AU-NYPL.
137 Michael Musto, “La Dolce column”, The Village Voice, October 25, 1988, Folder 1, Box 14, AU-NYPL.
ACT UP’s Media Committee set up a press table in front of the FDA building where they would direct the press to where the action was taking place, communicating with each other with walkie-talkies, every single member of the press is directed and each affinity group reports to the media committee right before an action is about to take place.138

Because the majority of ACT UP/NY members were young gay men, in the prime of their life, this often led to a very sexually charged atmosphere, a fact used by protesters to gain leverage with the media.139 ACT UP/NY member Chip Duckett, who was in the Media committee, remembered how they would take advantage of how the imagery of protests often combined a mix between violence and sex; “…it didn’t hurt that the pictures themselves were sexy…there were a lot of young people in tight clothes getting dragged down the street or whatever. Those are really sexy pictures…in terms of media pickup.”140

Another way ACT UP protesters used the media was the relationship a lot of the members had with different journalists covering the events. Jim Fourrat, who was also in the Media committee in ACT UP/NY remembers how they would assign ACT UP members with different reports they knew were in the closet and use the sexual relationship with these reporters to get their message out.141 It was a tactic used widely within ACT UP, Fourrat says about these tactics that “All is fair in love and war.”142

ACT UP members were separated into affinity groups for the FDA action and would meet separately to plan what they were going to bring to the action. Peter Staley mentioned in an interview that the fact that ACT UP was partitioned into affinity groups increased creativity within

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138 Kiki Mason, “FDA: The Demo of the Year”, The New York Native, October 24, 1988. Folder 1, Box 14, AU-NYPL.
140 Ibid.
142 Ibid.
the group in terms of who was going to come up with the most engaging visual; “...it almost created a competitive thing of “Who’s going to get the visual that ends up on the nightly news?”.”

“143 ACT UP/NY member Patrick Moore remembers having long meetings where they would discuss what kind of imagery they wanted to portray at the FDA action with his affinity group; “…we started talking about images, and we were talking about doctors and blood and, kind of, responsibility.”144 Moore and his affinity group decided to dress up as doctors, they wore white lab coats and spray painted them with red paint, carrying a sign that said “The government has blood on their hands”.145 Another affinity group called See Red, from ACT UP/NY, also decided to go with Moore’s affinity group idea and donned white lab coats. On the back of their lab coats they wrote down; “This demo made possible in part by a generous profit margin of Burrougs-Wellcome146, Limphomed147 and the FDA.”148

Peter Staley, wearing a Mishima-style headband and leather jacket, managed to elude the police and climbed on top of the FDA’s main entrance and swiftly got to work to hang a Silence=Death banner, and to up the theatrics he proceeded to set off smoke bombs. Kiki Mason, a reporter covering the event describes the action as “hysterical...Peter on top, the police in front of the entrance, demonstrators lying all over the place.”149 Staley then proceeded to put up posters along the FDA building façade, one read; “Time isn’t the only thing the FDA is killing”, another one had an acronym with the word AIDS spelling out “America Isn’t Doing Shit”.150

145 Ibid.
146 Company that makes AZT.
147 Company owns rights to AIDS related drug pentamidine.
148 Chris Bull, “Seizing Control of the FDA”, Gay Community News, October 16, 1988, Folder 1, Box 14, AU-NYPL.
149 Kiki Mason, “FDA: The Demo of the Year”, The New York Native, October 24, 1988. Folder 1, Box 14, AU-NYPL.
150 ACT UP/NOW Seize Control of the FDA, https://www.youtube.com/watch?v=s70aCOflRgY
Harris, one of the lawyers working within ACT UP/NY, remembered trying to dissuade Staley from doing that particular action, thinking it would have the potential of being seen as an incendiary device because of the smoke bombs, which would be a serious crime, and also because it could cause the police to escalate things, which would then draw attention away from their message. Thankfully, Staley’s action went on without any serious consequences, Harris remembers how Staley “looked like Karate Kid with his little headband, and he was shooting off his little bombs, and it looked like he was having fun.”\(^{151}\)

At another point during the daylong event, as promised to the press, protesters hoisted an effigy of Ronald Reagan and proceed to burn it, with cries from the crowd yelling “Seize control, seize control, seize control.”\(^{152}\)

ACT UP/NY member Stephen Gendin wore a leather jacket with the words “Cocksucker” on the back\(^{153}\), artist and ACT UP/NY activist David Wojnarowicz wore a jacket as well with an inverted pink triangle painted on the back and the following statement; “IF I DIE OF AIDS-FORGET BURIAL- JUST DROP MY BODY ON THE STEPS OF THE FDA”, the picture made the rounds on newspapers and was an inspiration for the Ashes Action that took place a few years later.\(^{154}\)

The image of Peter Staley on top of the FDA building façade, people running around yelling at the top of their lungs, members sitting down along a highway to prevent FDA workers from reaching work, the effigy of Reagan burning in the wind, these all provided an important image that obliterated the notion that those living with AIDS were helpless and weak. It changed


\(^{153}\) David Barr, “ACT UP Oral History Project”, Interview.

\(^{154}\) https://nblca.org/if-i-die-of-aids-forget-burial-just-drop-my-body-on-the-steps-of-congress-2/
the perspective of who was the person living with AIDS, Chip Duckett found this to be crucial for how ACT UP was perceived; “ACT UP was active…taking proactive steps, and it’s very difficult to take those photos and say, “These poor, sad creatures who are wasting away”, because it wasn’t the case… I think the overarching theme the media could take was that these people are not going to shut up and they are not going to back down.”

ACT UP’s use of emotion affected why people decided to join in the first place but it also affected how involved people were. Because a lot of the membership were either sick, or knew someone who was sick, the stakes for every action were raised because it was the difference between life and death for many of them. This meant that, as we saw in the Seize the FDA Action, protesters were not scared of being arrested, in fact, the more arrests they could get meant the action would be seen as more successful.

Protesters were fearless because in a way they had nothing to lose, they were energetic, creative and eloquent, and just as they had planned this proved to be a story the media was interested in telling. While the media had only been interested in telling the story of those with AIDS by portraying them as victims or weak, especially in TV and movies, actions like the one that took place at the FDA changed the tide of how people with AIDS were seen. The passion and overflowing of emotions displayed in these actions was palpable and in a way threatening to those in power, and together with ACT UP’s other tactics for gathering media attention, they would prove to be successful in finally getting organizations like the FDA and HHS to start listening to their demands.

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Chapter 3: What Happens after you Seize Control

As previously stated, the Seize the FDA Action was seen as a success by the ACT UP membership in two ways. This chapter will demonstrate that ACT UP activists believed that the action opened up a relationship between ACT UP members and the FDA as well as other government agencies and pharmaceutical companies, which in turn revolutionized the way AIDS
drugs were tested and released. So, in that sense, the original demands ACT UP had coming into the action were met.

The second way in which the action was seen as a success was that for ACT UP members, it changed the way people living with AIDS were perceived by the public and the government. While the media, especially on TV shows and movies, were portraying those living with AIDS as weak and dying, the FDA action showed a different side of those living with AIDS, they were portrayed as what they actually were, as young, strong, passionate, vibrant people fighting for their lives.

Before the FDA action, ACT UP as a group had been seen by the public as a defensive group, reacting to actions or remarks made by other organizations or the government. But with the FDA action, ACT UP made it clear that as a group they had their own agenda, they were versed in scientific language and had a plan on how to effectively make AIDS drug trials more efficient and inclusive, which in turn would make new AIDS drugs more available.\textsuperscript{157} And we can see this with the FDA handbook that was released prior to the action.

For David Barr, the shift happened almost overnight, he remembers how before the FDA demonstration, the FDA would rarely return their calls and would meet only with select people. After the demonstration, the FDA “returned the call the next day”\textsuperscript{158}, Barr argues that a relationship between ACT UP and the FDA became possible because of the action at the FDA, and furthermore, it transformed how the FDA viewed ACT UP activists; “…the relationship with the FDA was really transformed, it changed tremendously from where it started- you’re wasting my time- to we need to work with you people…. And the demonstration was…a really important piece in forcing the agency to realize they had to deal with us in a way they weren’t used to dealing with consumers.”\textsuperscript{159}

\textsuperscript{157} Gregg Bordowitz, “ACT UP Oral History Project”, Interview.
\textsuperscript{158} David Barr, “ACT UP Oral History Project”, Interview.
\textsuperscript{159} Ibid.
Jim Eigo who was in the Treatment and Data Committee of ACT UP/NY saw a clear change in how receptive those in the government were to the demands of groups like ACT UP following the FDA Action. For instance, the drug ganciclovir, the only drug available to treat cytomegalovirus infection, an infection which is common among AIDS patients and can lead to blindness, was approved less than a year after the FDA action. Indeed, reporters at the New York Times attributed the FDA’s expedited drug approvals as a result of pressure from activists (without explicitly mentioning ACT UP), the approval is quoted as being carried through after “…pressure from officials at the National Institutes of Health, from AIDS patients and their advocates.” 160

Another drug included in ACT UP’s list of demands when protesting the FDA, ddI, was also approved in September 1989, as quoted in a New York Times news article “In a major departure from their (FDA) usual cautious approach …” 161. The fact that the FDA was approving these drugs was even seen by the press as a departure from what the FDA usually did. Moreover, the article also mentions how this new approach on the part of the FDA was a result of “strenuous lobbying by advocates for people with AIDS.” 162, and that the drug would be distributed for free for patients who met certain requirements. The fact that the FDA approved drugs, meant that AIDS patients could get them covered through Medicaid and Medicare as well without having to pay out of pocket.

The approval of both these drugs, and the ones that would follow later on, were part of a policy the NIH called “parallel track”, which would allow AIDS patients too sick to participate in official experimental drug trials to take drugs currently being tested. Dr. Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases (NIH) mentions how parallel track was

the right thing to do; “It is clear from a humanitarian point of view that when there is practically no alternative treatments, we cannot say to patients, ‘If you are not eligible for clinical trials, too bad, you cannot get this drug.”

What goes unmentioned throughout the release of both these drugs, was how crucial ACT UP was in the creation of parallel track. In his oral history interview, Eigo mentions how in February 1988, he wrote a letter to Fauci with a proposal that the Treatment & Data group had been working on; “…saying that for people with AIDS who had exhausted AZT and had no treatment options and were too sick themselves to get into any clinical trials, that they should have what was known as- what we were calling parallel trials for people, so that they could get the only treatment options…And, our argument was, at the same time, you could also get dirty data on that person. The data might not be absolutely clean…you wouldn’t want that person to go off all other medicines he or she was taking…but that sort of real world data, itself, would be invaluable…” Eigo then mentions how only five months after initially sending the letter, Fauci got behind the idea, and renamed it parallel track to make it his own. But Eigo argues that it was because people in ACT UP, as well as other activists, were constantly finding holes in the system, had the knowledge to come up with sensible solutions, and had the numbers to pressure the powers that be that they were able to make these kinds of changes happen, that is how they got the FDA and NIH to finally listen.

By the end of the summer of 1989, the FDA had changed its relationship to ACT UP and was inviting ACT UP members into discussions related to drug testing and approval. Eigo was invited by the FDA to a meeting held by the FDA regarding the feasibility of parallel track, with ddl as the drug that was going to be tested. Eigo, and several other ACT UP members were allowed to speak and share their opinions as well as to demonstrate their extensive knowledge on these

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163 Ibid.
drugs and the drug approval process. The FDA used Eigo’s original proposal as a rough draft of what parallel track was going to become later on, and assigned Eigo to the commission that would help develop parallel track.  

Indeed, Eigo credits the evolution of drug cocktails to ACT UP’s pressure on the FDA and NIH since the introduction of parallel track coincided with getting a greater number of drugs approved in a faster manner, which then opened the idea of a cocktail to exist. He argues that the whole idea of an AIDS drug cocktail would have never happened unless there were a numerous amount of drugs available, which only happened because of the creation of parallel track.  

Rebecca Smith also agreed with the fact that it was partly ACT UP’s work, especially at the FDA (which led to the approval of multiple drugs), that led to protease inhibitors. While the idea of protease inhibitors came from pharmaceutical companies, it was the pressure from activists that lead to more trials, more drugs, and later on this resulted, not directly but partially, in the creation of protease inhibitors.  

So essentially ACT UP started out by having to protest outside of the FDA and NIH to have their demands heard, to being invited into important meetings related to AIDS research and treatment.  

It was the relentless work by ACT UP activists, of constantly finding companies and people to target, that led to the system into listening to their demands and start taking them seriously. Mark Harrington also credits the FDA demonstration as a shift in how drug companies and the government viewed ACT UP and its members. He remembers going into a meeting at Burroughs Wellcome with Peter Staley, who was at the time planning a zap occupation at their headquarters, 

\[166\text{ Ibid.} \]
\[167\text{ Ibid.} \]
\[169\text{ Rebecca Smith, “ACT UP Oral History Project”, Interview.} \]
and laying out their concerns and issues regarding AZT, which at the time was the main drug being tested, despite having already been approved by the FDA. Harrington was invited as “the science guy” representing ACT UP, and met with the head researcher of the company and had a “stimulating, weird conversation with him about science and business and price.” While nothing concrete came out of the meeting, Harrington remembers how Staley made a comment about the fountain in the lobby and how “it would look really great dyed red, blood red, in a demonstration.” A few months later, Staley would stage a protest at Burroughs Wellcome with other ACT UP activists, which would later result in the lowering of the price of AZT by 20%.

The NIH first started inviting ACT UP members to meetings regarding clinical trials, then they would assign different ACT UP members into AIDS Clinical Trials Group committees, were ACT UP members would push for funding for trials. David Kirschenbaum, also from the Treatment & Data committee talked about how at some point, people like Anthony Fauci, realized that it was more productive for them to work with ACT UP, because it would not only fulfill their own goals but also ACT UP’s. On the one hand, the NIH had passionate advocates making sure the trials were properly funded, and for ACT UP they had people on the inside, representing the interests of those living with AIDS. And this is a clear example of how they both benefited from working together.

It was the view of ACT UP activists that in order for AIDS research to advance in the right direction, the AIDS community had to be involved. And this was largely what they were aiming for when choosing to protest at the FDA and NIH, they wanted to be a part of the decision process that would directly affect them. After the FDA action, ACT UP members, especially those that

171 Ibid.
172 Ibid.
were part of the Treatment & Data committee were regularly invited to panels, meetings and conferences to the chagrin of the scientific community who was not used to dealing with activists.\textsuperscript{175}

But what made ACT UP so special, and this we got to see during the FDA demonstration is that they were not only about causing a scene and protesting, but rather ACT UP was made up of deeply knowledgeable individuals who were more than well versed on AIDS research and scientific language in general. For instance, at the Montreal Conference of AIDS in June 1989, there was a general discomfort by the scientific community due to the prominent and growing presence of activists, Fauci called for “an atmosphere of calm” prior to the conference. Of course, ACT UP along with other activist groups responded to Fauci’s call for calm with an action. Activists occupied the stage shortly before the official conference opening with signs and proceeded to shout demands followed by the reading of the Montreal Manifesto of the International Rights of HIV-Infected People.\textsuperscript{176} Following the stage occupation at the Montreal conference, ACT UP held a press conference in a packed room where they released their fifteen-page National AIDS Treatment Research Agenda. The National AIDS Treatment Research Agenda was a thoroughly researched agenda meant “to address the failings of the US government in research, treatment, and development of drugs to combat the AIDS epidemic.”.\textsuperscript{177} Just like they did prior to the FDA action when they released the “FDA handbook”, ACT UP members were once again proving the scientific community that were just as informed as they were, and had every right to be directly involved in AIDS treatment and research.

Jon Winkleman, of ACT UP/NY also agrees with the idea that the FDA action resulted in having people with AIDS part of the conversation and decision making, though also emphasized

\textsuperscript{175} Jim Eigo, “T & D Report”, June 1989, Folder 6, Box 62, AU-NYPL.
\textsuperscript{176} Jim Eigo, “T & D Report”, June 1989, Folder 6, Box 62, AU-NYPL.
\textsuperscript{177} ND, “ACT UP Press Release, AIDS Activists Announce US Treatment Research Agenda”, Folder 7, Box 12, AU-NYPL.
how these changes did not happen overnight, as opposed to others within ACT UP that saw changes right away. As previously stated, some ACT UP members were invited to work on the AIDS Clinical Trial Groups, were they had the chance to share their views on how to make clinical trials more efficient and fair.\textsuperscript{178} It also put pressure on drug companies to pay attention to their demands, Winkleman says; “Drug companies were meeting with us, because drug companies saw how angry we were and saw we were causing a mess. So they wanted our input.”\textsuperscript{179}

As we have seen here, ACT UP had significant tangible successes following the FDA action, achievements that can be traced back as a before/after, even though as some ACT UP members have mentioned, there were other small mitigating factors that worked alongside the pressure created by the FDA action.

One of the side mitigating factors worth mentioning, since it relates to the FDA action as well, was the fact that in the view of a lot of activists, the reason why pharmaceutical companies went along with ACT UP in their demands of restructuring the way the FDA conducted trials, was that it was in their best interest to deregulate the drug industry.\textsuperscript{180} Garance Frank-Ruta, a member of the Treatment & Data committee also echoed this sentiment while giving credit to the FDA reform. Frank Ruta believed that the FDA action resulted in speeding up the drug approval process and reformed it in a way that gave drug companies monetary incentives to conduct research on new drugs, which in turn benefited people with AIDS. However, she does recognize that at the same time, pharmaceutical companies and politicians would benefit from a weaker FDA as well; “….I don’t think that we realized at the time that this was part of the broader gutting of the FDA….that there was a lot of political agendas that we just happened to be in sync with.”\textsuperscript{181}

\textsuperscript{179} Ibid.
\textsuperscript{180} Rebecca Smith, “ACT UP Oral History Project”, Interview.
Rebecca Smith, also working in the same committee as Frank-Ruta, agreed with the fact that part of the reason why ACT UP gained the support of pharmaceutical companies was partly due to pharmaceutical companies’ desire to deregulate the drug industry, something that would give them more freedom in terms on how quickly they could release drugs and how much they could charge for them. This also tied with the current Republican government and their desire to decentralize and keep the government small, she argues; “AIDS made bedfellows out of AIDS activists and deregulationist Republicans.”

The second way in which ACT UP activists saw the Seize the FDA Action as a success was the fact that in their view, it changed the way they were perceived by the outside world; “…it helped change the way AIDS was viewed and the way people with AIDS were viewed.” They were no longer weak, dying AIDS patients, but rather regular men and women putting their bodies on the line, demanding change and attention from the government.

For Chip Duckett, there was a clear change in perception as to how they were portrayed in the media after the FDA action; “…those media images were starkly different than they had been previously….the biggest achievement was changing the dialogue…on the image of the person with AIDS…ACT UP was a game changer in the perception and in the coverage and in the conversation.” Douglas Crimp, also from ACT UP/NY saw a clear change in how the press viewed AIDS in general; “Particularly in relation to how AIDS was talked about in mainstream press, for example. I think we really did have an effect on that.”

For David Barr, because the FDA was the first ACT UP national protest which garnered the most visibility compared to previous New York based ones, it allowed all of the country to

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182 Rebecca Smith, “ACT UP Oral History Project”, Interview.
184 Ibid.
have a different view of what a person with AIDS looks like. Barr argues that “through the work of ACT UP…we developed a vision of the person with AIDS as hero. And that really was personified at the FDA. Look at these people, they’re fighting for their lives. And they may not look like we all look out there…but, oh, they’re dying, and they want medicine.” 186 In other words, for Barr, the protest at the FDA made people with AIDS relatable, and hence, made them and their demands and actions sympathetic to the general public. With the FDA action, according to Barr, ACT UP solidified the image of what an AIDS activist looked like, and it was one where they were the heroes of the story.

Peter Staley also agrees with the fact that it changed the perspective, but more generally, changed the perspective about gay men and lesbians; “They perceived us as weak until ACT UP came along, and then I think they- maybe at times feared us, but definitely respected and kind of, there was an admiration and understanding of and a respect of what we did.”187 While Staley is talking about ACT UP’s achievements in a broader sense, the FDA action definitely helped the perspective of a united front among gay and lesbians and also promoted the image of AIDS activists as passionate and driven.

Along the same lines as Staley, Jim Fourrat, when thinking about ACT UP as a whole and the image it displayed, argues that ACT UP managed to empower people by presenting itself as a group that were not afraid of dying, but rather angry at the silence around the deaths happening. Fourrat says; “At least externally….it gave people that were stigmatized and presented a visual image for the world to see of people that were not afraid of being sick.”188 This is a good example of how important the images at the FDA action were, the lab coats with blood, the angry chants, the die-ins, all these images helped people see beyond the illness, and see them/themselves as activists.

For Jay Blotcher, it was also the idea of empowerment that remained as a lasting legacy of ACT UP, something made possible by actions like the FDA. Blotcher argues that this empowerment allowed activists to be able to challenge both the government and the medical community; “ACT UP’s self-empowerment program inspired many other people…to change the model of their interaction with the government and the medical industry.” Through actions like the FDA, ACT UP activists openly challenged the government and big pharmaceutical companies, inspiring both those within the movement and those looking from the outside in.

For Bordowitz, there was also a shift in the language that ACT UP decided to use that came out of the FDA action, a development that affected and empowered ACT UP members. Bordowitz argues that he started using a specific kind of language that would sound like the kind an activist would use, the whole “Seize Control of the FDA” came from Bordowitz. And whilst it was shocking to many members at first, Bordowitz was insistent claiming “This is what has to be. It has to be what we are just going to take over the agency. The agency is not being run in our 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.”189 The FDA action contributed to the whole idea of self-determination, and we can clearly see that when we look at the steps ACT UP took to inform themselves and come up with solutions to issues they had with particular agencies.

Similarly, to Bordowitz, ACT UP/NY member Herb Spiers also agreed with the fact that actions like the one held at the FDA solidified the idea of normal citizens having power to challenge the government and have their demands met; “…there was an awareness brought not just to the American public but to the world public…that decisions regarding medicine and science could be affected by ordinary citizens coming together and…doing something.”190

For Rebecca Smith the concept of self-determination was also an idea that solidified itself after the FDA action; “…a person living with AIDS, people having a voice and a representation of their own concerns, and the concept that this can affect beneficially the way science is done, the articulation that every arm of every clinical trial needs to be a viable treatment option.”¹⁹¹ This also emphasized the idea that ACT UP came up with of thinking of clinical trials as health care since a lot of the times, experimental drugs were the only treatment available for a lot of people.

As we have seen in this chapter, ACT UP activists for the most part, saw the events at the FDA as a success. It opened the door for people with AIDS to become directly involved in research and treatment by being invited by the NIH, the FDA and drug companies as part of their panels. Their opinions were valued and sought after, like when parallel track was launched. Furthermore, while it is hard to argue if there was an actual shift in how ACT UP activists were perceived by the media and the rest of the American population, the fact that ACT UP activists themselves felt that a shift happened is crucial because it gave them the confidence and determination to continue fighting.

¹⁹¹ Rebecca Smith, “ACT UP Oral History Project”, Interview.
Conclusions

ACT UP's “Seize Control of the FDA” action encapsulated how ACT UP NY worked as a group, what drove activists to participate and what differentiated them from other activist groups at the time. The role that emotions like anger, rage and sadness played in ACT UP’s inception and development is crucial in understanding what set them apart.

ACT UP activists were passionate, driven individuals, and the lack of action by the government led many activists to start doing their own research, educating themselves and the rest of the membership of ACT UP on the science behind AIDS drugs research and development. It was because activists were so well informed that they could go toe to toe with any health official or doctor when it came to talking about AIDS. Moreover, because it was personal to their lives or/and that of their loved ones, they were constantly searching for more efficient ways to run drug trials and increase treatment access. The FDA handbook is a solid example of how educated ACT UP activists were, moreover, it also shows that they were not just criticizing the FDA but had well thought solutions and ideas for how to improve the current system. They wanted to take back control of a system that had failed them, and making it work to the benefit of their cause.

As we have seen as well, part of the reason why the FDA action was so successful was that they were very self-aware as to how they were perceived, and if what the media wanted was a loud protest with arrests, then they were going to deliver. For ACT UP activists, it was about the image that would linger that mattered, the picture of an activist with fake blood on their clothes, the picture of an activists being dragged in handcuffs, a huge banner being draped over the entrance of the FDA. And in this sense, it was the release of emotions such as anger and rage that made the FDA action so packed with lingering images that enabled the action to be printed on the cover of newspapers nationwide.
Furthermore, there is a lot to say about how because of ACT UP these emotions, felt by so many of the members, were able to be channeled into something productive and meaningful. They weren’t just angry, they were angry at the government, they were angry at the NIH, they were angry at the FDA, and because of ACT UP activists had a way to channel that anger to those responsible.

It was also that anger and rage that ACT UP embodied that intimidated the government, healthcare officials and pharmaceutical companies. A lot of the reasons why the FDA and the NIH started working with ACT UP activists was out of necessity, and out of their fear of controversy and being targeted. It was a turning point for ACT UP activists after the FDA because they were now being invited into the conversation. They were no longer relegated to the sidelines, but rather were welcomed into official meetings which allowed them to pursue their own agendas in a more official manner.

While other authors have written extensively on ACT UP, the only author I’ve come across to deal with how emotions shaped the movement was Deborah Gould. I feel this thesis is a supplement to the work that she’s doing, especially because I chose to focus on one action and how emotions interacted in the shaping and execution of the action at the FDA. While a lot of work has been done linking social movements and emotion, I think what sets the AIDS epidemic apart is the immense loss of young lives in such a short period of time that triggered so many emotions, and that is something worth exploring further.

While I have shown how emotion and activism were intertwined in ACT UP, there were still limitations to my research that are worth exploring. What proved the most difficult was finding a way to explore how emotion moves through people and in this case actions. While it is clear to see that emotions such as anger and rage fueled ACT UP activists into action, especially for the FDA action, it was at times challenging to prove how these two were connected. Especially when focusing on one action. Another issue I came across, which is not surprising when dealing with interviews, is that there is a lot of self-awareness by activists to the point where it is hard to see
the story from another perspective but theirs. While it is true, that even back then, a lot of activists knew that the work they were doing was significant, and even historical, some of the activists gave ACT UP as an organization too much credit for enacting change without considering mitigating factors that worked in their favor.
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