

■ ACT UP Founding Document and Speech

Dates: March 1987; May 8, 1988

Author: AIDS Network, Vito Russo

Genre: broadside; speech

Summary Overview

The AIDS epidemic began in 1981, HIV was identified as its cause in 1983, the first test was developed in 1985, and the first effective drug was released in 1987. The epidemic has since claimed 650,000 lives in the United States across all ethnic, sexual, and class groups, but some of the earliest affected groups were gay men and IV drug users in urban areas. When a city, state, or federal governmental response to counter the epidemic failed to materialize, urban gay communities organized support systems to cope with a frightening and poorly understood illness. The release of the drug AZT in 1987, however, changed the calculus for advocates of people with AIDS. The first effective, though toxic, treatment and an array of other experimental drugs led activists to focus on drug development and regulation. The rise of the AIDS Coalition to Unleash Power (ACT UP) in 1987 and Vito Russo's speech one year later in 1988 represented how promise and desperation met to challenge widespread apathy and neglect.

Defining Moment

Against the backdrop of Ronald Reagan's presidency and renewed conservatism in the United States, ACT UP aimed to counter prejudice, stigma, and ignorance about HIV and AIDS. Their first protest focused on the release of experimental drugs and the elimination of the double-blind clinical trial. This type of experiment offered one group a placebo, which acted as a control for the effects of a tested drug. Since the 1960s and after controversies when improperly tested drugs harmed patients, the randomized double-blind clinical trial became the gold standard for clinical research.

ACT UP challenged researchers' preferences on the grounds that it was unethical to provide a placebo to a dying patient. In any case, researchers quickly realized that the largely sexual mode of HIV transmission meant that patients often knew each other and shared information. Those enrolled in clinical trials performed their

own guerrilla medicine by taking their pills to independent chemists to determine whether they received an experimental compound or a placebo. Some cut pills to share the experimental drug with those who received a placebo. These actions undercut the point of the double-blind trial and altered the data researchers were seeking. It became increasingly clear to both researchers and activists that the specific profile of HIV disease did not fit the double-blind trial. A tightly knit community that shared information and procured alternative treatments frustrated the efforts of scientists to obtain controlled data.

ACT UP's raucous protests and public interventions did disturb the complacent public, but their target lay squarely on the governmental biomedical complex of the Centers for Disease Control and Prevention, the Food and Drug Administration, and the National Institutes of Health's Allergy and Infectious Diseases unit. This meant that ACT UP increasingly engaged experts more than it challenged laymen. The entry of ACT UP into rarified research and development spaces—areas normally requiring many years of education and credentials—led to AIDS activism that challenged the credibility of scientists. AIDS activists suggested that they were the experts on their own disease. When Vito Russo delivered his "Why We Fight" speech before the New York state government in Albany or the Department of Health and Human Services in the nation's capital, it represented the finest combination of ACT UP's direct action tactics and its method of centering people with AIDS as the most knowledgeable.

Author Biography

Vito Russo, born July 11, 1946, was a film historian, writer, gay activist, and member of the Gay Activists Alliance. For a decade, between 1972 and 1982, Russo toured the United States and delivered a series of lectures on the depiction of lesbian, gay, bisexual, and

transgender (LGBT) characters in Hollywood films. In 1983, Russo produced the news series *Our Time* for WNYC-TV, one of the earliest public access television programs to focus on LGBT lives. Russo cofounded the Gay and Lesbian Alliance Against Defamation in 1985,

a watchdog organization to monitor discrimination against LGBT people in the media. Russo was diagnosed with HIV in 1985 and passed away from AIDS-related causes in 1990.

HISTORICAL DOCUMENT

[Flyer of the first ACT UP action March 24, 1987, Wall Street, New York City]

NO MORE BUSINESS AS USUAL!

Come to Wall Street in front of Trinity Church
at 7AM Tuesday March 24 for a

MASSIVE AIDS
DEMONSTRATION

To demand the following

1. Immediate release by the Federal Food & Drug Administration of drugs that might help save our lives.

These drugs include: Ribavirin (ICN Pharmaceuticals); Ampligen (HMR Research Co.); Glucan (Tulane University School of Medicine); DTC (Merieux); DDC (Hoffman-LaRoche); AS 101 (National Patent Development Corp.); MTP-PE (Ciba-Geigy); AL 721 (Praxis Pharmaceuticals).

2. Immediate abolishment of cruel double-blind studies wherein some get the new drugs and some don't.

3. Immediate release of these drugs to everyone with AIDS or ARC.

4. Immediate availability of these drugs at affordable prices. Curb your greed!

5. Immediate massive public education to stop the spread of AIDS.

6. Immediate policy to prohibit discrimination in AIDS treatment, insurance, employment, housing.

7. Immediate establishment of a coordinated, comprehensive, and compassionate national policy on AIDS. President Reagan, nobody is in charge!

AIDS IS THE BIGGEST KILLER IN NEW YORK
CITY

OF YOUNG MEN AND WOMEN.

Tell your friends. Spread the word. Come protest
together.

7 AM ... March 24 ... You must be on time!

AIDS IS EVERYBODY'S BUSINESS NOW.

The AIDS Network is an ad hoc and broad-based
community of AIDS-related organizations
and individuals.

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[Speech by Vito Russo, Albany NY May 9, 1988]

A friend of mine in New York City has a half-fare transit card, which means that you get on buses and subways for half price. And the other day, when he showed his card to the token attendant, the attendant asked what his disability was and he said, I have AIDS. And the attendant said, no you don't, if you had AIDS, you'd be home dying. And so, I wanted to speak out today as a person with AIDS who is not dying.

You know, for the last three years, since I was diagnosed, my family thinks two things about my situation. One, they think I'm going to die, and two, they think that my government is doing absolutely everything in their power to stop that. And they're wrong, on both counts.

So, if I'm dying from anything, I'm dying from homophobia. If I'm dying from anything, I'm dying from racism. If I'm dying from anything, it's from indifference and red tape, because these are the things that are preventing an end to this crisis. If I'm dying from anything, I'm dying from Jesse Helms. If I'm dying from anything, I'm dying from the President of the United States. And, especially, if I'm dying from anything, I'm dying from the sensationalism of newspapers and magazines and television shows, which 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—I'm dying from the fact that not enough rich, white, heterosexual men have gotten AIDS for anybody to give a shit. You know, living with AIDS in this country is like living in the twilight zone.

Living with AIDS is like living through a war which is happening only for those people who happen to be in the trenches. Every time a shell explodes, you look around and you discover that you've lost more of your friends, but nobody else notices. It isn't happening to them. They're walking the streets as though we weren't living through some sort of nightmare. And only you can hear the screams of the people who are dying and their cries for help. No one else seems to be noticing.

And it's worse than a war, because during a war people are united in a shared experience. This war has not united us, it's divided us. It's separated those of us with AIDS and those of us who fight for people with AIDS from the rest of the population.

Two and a half years ago, I picked up *Life* Magazine, and I read an editorial which said, "it's time to pay attention, because this disease is now beginning to strike the rest of us." It was as if I wasn't the one holding the magazine in my hand. And since then, nothing has changed to alter the perception that AIDS is not happening to the real people in this country.

It's not happening to us in the United States, it's happening to them—to the disposable populations of fags and junkies who deserve what they get. The media tells them that they don't have to care, because the people who really matter are not in danger. Twice, three times, four times—*The New York Times* has published editorials saying, don't panic yet, over AIDS—it still hasn't entered the general population, and until it does, we don't have to give a shit.

And the days, and the months, and the years pass by, and they don't spend those days and nights and months and years trying to figure out how to get hold of the latest experimental drug, and which dose to take it at, and in what combination with other drugs, and from what source? And, how are you going to pay for it? And where are you going to get it? Because it isn't happening to them, so they don't give a shit.

And they don't sit in television studios, surrounded by technicians who are wearing rubber gloves, who won't put a microphone on you, because it isn't happening to them, so they don't give a shit. And they don't have their houses burned down by bigots and morons. They watch it on the news and they have dinner and they go to bed,

because it isn't happening to them, and they don't give a shit.

And they don't spend their waking hours going from hospital room to hospital room, and watching the people that they love die slowly—of neglect and bigotry, because it isn't happening to them and they don't have to give a shit. They haven't been to two funerals a week for the last three or four or five years—so they don't give a shit, because it's not happening to them.

And we read on the front page of *The New York Times* last Saturday that Anthony Fauci now says that all sorts of promising drugs for treatment haven't even been tested in the last two years because he can't afford to hire the people to test them. We're supposed to be grateful that this story has appeared in the newspaper after two years. Nobody wonders why some reporter didn't dig up that story and print it 18 months ago, before Fauci got dragged before a Congressional hearing.

How many people are dead in the last two years, who might be alive today, if those drugs had been tested more quickly? Reporters all over the country are busy printing government press releases. They don't give a shit, it isn't happening to them—meaning that it isn't happening to people like them—the real people, the world-famous general public we all keep hearing about.

Legionnaire's Disease was happening to them because it hit people who looked like them, who sounded like them, who were the same color as them. And that fucking story about a couple of dozen people hit the front page of every newspaper and magazine in this country, and it stayed there until that mystery got solved.

All I read in the newspapers tells me that the mainstream, white heterosexual population is not at risk for this disease. All the newspapers I read tell me that IV drug users and homosexuals still account for the overwhelming majority of cases, and a majority of those people at risk.

And can somebody please tell me why every single penny allocated for education and prevention gets spent on ad campaigns that are directed almost exclusively to white, heterosexual teenagers—who they keep telling us are not at risk!

Can somebody tell me why the only television movie ever produced by a major network in this country, about the impact of this disease, is not about the impact of this

disease on the man who has AIDS, but of the impact of AIDS on his white, straight, nuclear family? Why, for eight years, every newspaper and magazine in this country has done cover stories on AIDS only when the threat of heterosexual transmission is raised?

Why, for eight years, every single educational film designed for use in high schools has eliminated any gay positive material, before being approved by the Board of Education? Why, for eight years, every single public information pamphlet and videotape distributed by establishment sources has ignored specific homosexual content?

Why is every bus and subway ad I read and every advertisement and every billboard I see in this country specifically not directed at gay men? Don't believe the lie that the gay community has done its job and done it well and educated its people. The gay community and IV drug users are not all politicized people living in New York and San Francisco. Members of minority populations, including so called sophisticated gay men are abysmally ignorant about AIDS.

If it is true that gay men and IV drug users are the populations at risk for this disease, then we have a right to demand that education and prevention be targeted specifically to these people. And it is not happening. We are being allowed to die, while low risk populations are being panicked—not educated, panicked—into believing that we deserve to die.

Why are we here together today? We're here because it is happening to us, and we do give a shit. And if there were more of us AIDS wouldn't be what it is at this moment in history. It's more than just a disease, which ignorant people have turned into an excuse to exercise the bigotry they have always felt.

It is more than a horror story, exploited by the tabloids. AIDS is really a test of us, as a people. When future generations ask what we did in this crisis, we're going to have to tell them that we were out here today. And we have to leave the legacy to those generations of people who will come after us.

Someday, the AIDS crisis will be over. Remember that. And when that day comes—when that day has come and gone, there'll be people alive on this earth—gay people and straight people, men and women, black and white, who will hear the story that once there was a terrible disease in this country and all over the world, and that a brave group of people stood up and fought and, in some cases, gave their lives, so that other people might live and be free.

So, I'm proud to be with my friends today and the people I love, because I think you're all heroes, and I'm glad to be part of this fight. But, to borrow a phrase from Michael Callen's song: all we have is love right now, what we don't have is time.

In a lot of ways, AIDS activists are like those doctors out there—they're so busy putting out fires and taking care of people on respirators, that they don't have the time to take care of all the sick people. We're so busy putting out fires right now, that we don't have the time to talk to each other and strategize and plan for the next wave, and the next day, and next month and the next week and the next year.

And, we're going to have to find the time to do that in the next few months. And, we have to commit ourselves to doing that. And then, after we kick the shit out of this disease, we're all going to be alive to kick the shit out of this system, so that this never happens again.

VITO RUSSO

GLOSSARY

Ampligen: a chronic fatigue drug

Anthony Fauci: the director of the National Institute of Allergy and Infectious Diseases

DDC: a reverse transcriptase inhibitor antiviral drug

direct action: protest tactic to highlight existing problem and potential solution

GLOSSARY CONTINUED

Jesse Helms: US senator from North Carolina and leader of conservative movement

Legionnaire's disease: a type of pneumonia that became an outbreak in Philadelphia in 1976

Michael Callen: founder of People with AIDS Self-Empowerment Movement and founding board member of the Community Research Initiative, the National Association of People with AIDS, People with AIDS (PWA) Coalition, and the PWA Health Group

placebo: a substance that has no therapeutic effect

ribavirin: a nucleoside analogue antiviral drug

Document Analysis

Vito Russo's gaunt body and his speech "Why We Fight" characterized the most powerful, intimate, and personal of ACT UP's direct actions. Despite his poor health, Russo stood before the New York state government and the Department of Health and Human Services to argue that his deterioration was an unnecessary outcome of a government and society that ignored a growing epidemic. The speech's refrain "If I'm dying from anything. . ." pointed to intersecting modes of discrimination such as homophobia, racism, and class. Russo challenged the depiction of AIDS as a question of an in-group and an out-group. He sought to dispel the notion that white or heterosexual people had nothing to fear from AIDS.

Russo's speech showed the urgency of the people with AIDS movement seven years into the epidemic. Instead of conservatism, Russo and the coalition of AIDS activists argued for immediate action on experimental drugs, clinical trials, affordable prices, massive public education, anti-discrimination policy, and coordinated care at the city, state, and federal level. He argued that ACT UP fought because no one else did and that widespread apathy fueled the epidemic. In each example, Russo showed how policy made the difference between life and death—from the family to the media to the hospitals. For the HIV-positive and those who became sick, AIDS influenced nearly every facet of life.

The rhetorical questions Russo posited also dealt with how stigma against sexual minorities and racialized groups narrowed the possibilities for education and the deployment of government resources. Even though epidemiologists indicated that the epidemic primarily

harmed gay men and IV drug users, educational efforts often featured white families and populations who were at lower risk of HIV infection. Russo called on education that directly addressed the populations most at risk, even if this challenged the mores of conservative politicians who preferred to ignore groups they deemed deviant.

Even though Russo envisioned a day when AIDS would be consigned to the past, he lamented the fact that AIDS activists were busy performing triage and "putting out fires." Despite ACT UP's ramped-up organization, Russo argued that activists needed time to strategize and think about the future. The promise of effective drugs pointed the way towards strategies that would allow people living with AIDS and their caretakers to agitate for better drugs, but also broader education and awareness.

Essential Themes

Using the sight of his body and the rage of his voice, Russo counteracted the notion that the epidemic was a threat that would soon dissipate. He used rhetoric and anger to bring attention to an emergency. Russo insisted that apathy about sickness in one group threatened everyone by encouraging individualism at the expense of collective responsibility. Implicitly, Russo's address implied that the US response to the epidemic threatened to undo democracy and humanitarianism within the nation. In the short term, Russo's speech showed that AIDS was, in fact, a dire situation for one of the world's most industrialized economies. In the long-term, Russo's speech galvanized the people with AIDS movement and justified their anger at neglect.

Scientists and government regulators of pharmaceu-

ticals found themselves on the defensive when ACT UP's message of governmental neglect began to influence the mainstream. Compared to prior illnesses, they believed that the development of the first effective drug within six years of the epidemic was rapid. In their view, the government responded as prudently as it could, in spite of the epidemic's unclear origins in its first two years. Eventually, scientists and activists came to see that they shared mutually overlapping interests. Activists needed scientists for their expertise and the ability to conduct experiments and develop drugs. Scientists needed activists for their experience and access to trial participants and, often, knowledge about the latest promising therapies issuing from other pharmaceutical centers in Europe and elsewhere.

Nonetheless, it became clear that the experience of people with AIDS and their own knowledge of the illness challenged the boundaries of expertise that had governed the doctor-patient relationship for much of the twentieth century. Like the breast cancer activists preceding them, the people with AIDS movement saw power in organizing their own to show how doctors and scientists could improve their practice. This mode of democratic organizing has profoundly disrupted the notion of an inviolate expert and empowered patients to learn about

their illness and research the latest treatments. As the epidemic continues to surge, notably among men who have sex with men, young people, African Americans, the incarcerated, and under- and uninsured rural populations in the United States, policy, advocacy, and activist groups today continue to incorporate the lessons and tactics of 1987 and 1988 in the continued fight against HIV and AIDS.

—George Aumoithe, MA

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