

## ACTing UP to Change the World

The human immunodeficiency virus or acquired immune deficiency syndrome (HIV/AIDS) epidemic began in the early 1980s. This was a socially bound epidemic (Wright et al., 2016) rooted in both the then taboo nature of the homosexual community and an initial lack of understanding of the cause of the disease from the scientific community (McClintock, 2017). The lack of scientific cause for HIV/AIDS was complicated more as the virus appeared to mostly infect already marginalized groups who did not have comprehensive access to services or felt able to access services for fear of judgement (Wright et al., 2016). The lack of understanding and fear that occurred in this time were not helped by the Department of Public Health Services originally naming the disease as gay-related immune deficiency (GRID) (Witcher, 2019). This name only reinforced that there were disparities and bias in healthcare in the mid to late 1900s, as HIV became referred to as the 'gay plague' by the media (Witcher, 2019). Society as a whole was deeply homophobic and this meant that care for many people with HIV was subpar because they were marginalized by society and in turn the medical community (Wright et al., 2016). A group that became especially vulnerable in the late 1900s was the black gay community, as they were being discriminated based on race, sexual orientation, and in some cases socioeconomic status as well (Foster & Gaskins, 2013). The Aids Coalition to Unleash Power, or ACT UP, emerged in response to the oppression and silence of people with HIV/AIDS. The organization gave a voice to those who were being silenced by the stigma of HIV/AIDS and ignored by the medical community.

The start of the HIV/AIDS epidemic brought to light the injustices in society that had been hidden in the shadows out into the light. There were issues with equity in healthcare, housing, and public assistance. One issue that happened to many is that there was a lack of organization in many healthcare systems which led to neglect of care. Many hospitals, clinics and public health offices did not have information about HIV/AIDS and handled diagnoses very

poorly (Berger, 2006). A strong connection between HIV/AIDS and homelessness or housing insecurity was also found. This led HIV to be considered a ‘disease of poverty’, as the disease can be directly connected to socioeconomic status (Julie Hilvers et al., 2016). There was also a push in 1989 for improved housing for people with AIDS. At that point in New York City there were shelters for homeless people with AIDS but there was no permanent housing options for homeless people with AIDS (Hubbard, 2012). There was also a lack of benefits for affected people unless they had the specific diagnosis of AIDS. This diagnosis usually did not include women or drug users and they received no benefits (Hubbard, 2012).

The role of the media in the HIV/AIDS epidemic was unprecedented at the time. It was described by the Associated Press as “a wave of pneumonia and cancer [that was] killing homosexual men across the country” (Witcher, 2019). While some helpful information was reported by the media, most of what was reported spread fear and confusion. However, headlines such as “Being Gay Is a Health Hazard” perpetuated misinformation and put more fear into the public who then turned fear into hatred of the ‘other’. This fear was worsened by the lack of understanding in the scientific community about HIV/AIDS, its causes, transmission route, and potential cures. Most people assumed that contracting HIV meant that they would die (McClintock, 2017). Since the cause of HIV/AIDS was mostly unknown at that time, many of the conversations had about AIDS were centered on the morality of homosexuality and the health risk that people perceived that gay people had created (Witcher, 2019). This perception led to most of the conversations in the early 1980s being centered around politics regarding homosexuality rather than researching and demystifying AIDS, and any research that was discussed was easily taken out of context. For example, in 1983 health professionals began to discuss that AIDS was most likely being spread through ‘intimate contact’ and bodily fluids such as blood and semen. Some outlets took this information and ran stories that AIDS could be transmitted through blood donations and warned about the threat of homosexual blood donations (Witcher, 2019). This is a stigma that continued into the 21<sup>st</sup> century.

The HIV/AIDS epidemic was largely ignored by many people in power. Ronald Ragan did not address the AIDS epidemic until 1984. Whenever the White House Press Secretary, Larry Speakes was asked about AIDS, he responded with homophobic jokes and never an answer to the question (Witcher, 2019). Like the Press Secretary, many other politicians dismissed the urgency for HIV/AIDS research and medication because they viewed the population that was afflicted as disposable and unimportant minorities in society (Hubbard, 2012).

By 1987 there were four hundred thousand HIV deaths in the United States with more than five million deaths worldwide. While this number is staggering, there was no real call to action by governments and the main support system for those with HIV in the United States came from the LGBT community. The LGBT community focused on supporting, comforting, and helping those who received HIV diagnosis through various avenues. These included helping them get to doctors' appointments, buying groceries for those whose diagnosis kept them from working, and even helping with end of life planning. These activities were not enough for some members of the LGBT community; they wanted to be doing more and affecting change to improve their and others lives who received an HIV diagnosis (Aizenman, 2019). ACT UP was formed in March 1987 in response to the frustration that the gay community felt because AIDS was not being taken seriously by the media or government officials. ACT UP is a "non-partisan group united in anger and committed to direct action to end AIDS" (*ACT UP NY | End AIDS!*, 1987).

ACT UP was preceded by the Gay Men's Health Crisis (GMHC). GMHC started the fight for improved medical access and research. GMHC pushed for 'safer sex' guidelines and organized consistent care for people with AIDS (REED, 2019). As the epidemic continued to grow in scale, and as there was no assistance from the federal government, it became apparent that more needed to be done to support those with HIV/AIDS (REED, 2019). As a result, one of ACT UP's first protest was at Wall Street to protest the cost of AIDS treatments. In 1987 the

Federal Drug Administration (FDA) approved the first medication to treat the symptoms of AIDS, AZT. The cost of a year of AZT in 1987 was \$10,000, which is \$23,000 currently (Hubbard, 2012). The need for more treatment options was the first medication to be approved by the FDA and the only one on the market at the time. This prompted another protest in 1988. The idea was to 'seize the FDA' as a way to push the FDA to approve and release drugs faster. The phrase that they kept repeating at this protest was "drugs into bodies" as the most important thing at the time was getting medication to those in need (Hubbard, 2012). The goal of these protests to was disrupt "business as usual" (Hubbard, 2012).

ACT UP used many tools to protest and fight for a change in legislation and medical treatment. ACT UP relied heavily on the arts, visual media, and how media covered protests. These protests were largely started because the struggle of people with AIDS was being ignored by the government and the media. They had four major targets for protest: mass media, corporations, advertising, and the arts (REED, 2019). In May of 1988, Vito Russo made a speech on the steps of the capitol building in Albany, NY. He said "living through AIDS is like living through a war that is happening only for those who happen to be in the trenches" (Hubbard, 2012). ACT UP used the tactics of civil disobedience as a way to gain media attention so that they could control the story that the media presented. They did this was including statistics in their posters and chants to remind people how common it was to die from AIDS. ACT UP also increased the knowledge of the general public by creating pamphlets. ACT UP thought that part of the solution to the AIDS crisis was through educating the public on the reality of people with AIDS. ACT UP thought that "power and knowledge are inseparable" (REED, 2019).

ACT UP overcame many obstacles to become successful. They were speaking out for marginalized groups including homosexuals, intravenous drug users, and sex workers. This meant that ACT UP had to bring taboo topics out into the public sphere and force people to listen to what they had to say. ACT UP used many techniques including public political shaming of officials and companies whose inaction lead to many deaths of people with AIDS, and

demonstrations such as “die-ins” where protesters made a point about the amount of people dying and the harm that was being done by this inaction (REED, 2019). Members saw the fight that they undertook was a “war” and they were “fighting for [their] lives” (Hubbard, 2012). There was a general belief in the early 1990s that while people may not be able to fight AIDS, they could and would fight the system for better treatment and access to treatment (Hubbard, 2012). ACT UP believed that “Silence=Death”, and with that motto ACT UP was always vocal and pushing boundaries to bring about a change (REED, 2019). ACT UP was thoughtful and purposeful about symbols. The symbol that they associated with themselves was a pink triangle on a black background. Similar to the symbol that gay prisoners were forced by the Nazis to wear in concentration camps, the founders of ACT UP believed that if the topic of AIDS stayed silent then the amount of deaths could be comparable to the Holocaust. However, the triangle of ACT UP was pointed up to show that they could rise above (REED, 2019).

The treatment of drug users became actively discussed with the AIDS epidemic as scientists discovered, “AIDS was ‘spread by sexual contact or by shared needles’” (Witcher, 2019). While this was very useful insight into how AIDS was spread, it also brought into light another group that could be oppressed. ACT UP protested at the National Institute of Health in May of 1990, where they were pushing for increased demographics to be included into drug trials for AIDS medication. ACT UP wanted a more diverse group to be included in AIDS studies and trials, specifically they wanted people of color, drug users, and homeless to be included (Hubbard, 2012). A subset of drug users that were especially stigmatized were female drug users. For many of these women being diagnosed as HIV positive resulted in “feeling worth less than an animal laying out to die” (Berger, 2006) This occurred to women diagnosed in health departments, neighborhood clinics, substance abuse centers, prisons, and public hospitals. These women cited that the materials on HIV/AIDS that they were given did not fit their situations as women and drug users (Berger, 2006). Many of these women believed that they received biased treatment because they were or had been drug users. The medical profession

believed that because they were women, they were assumed to be drug users as they were women with AIDS, even if their drug use status was not known by the doctors or medical professionals. Ads such as “Get high, get stupid, get AIDS” just perpetuated the idea that if women became HIV positive then they were most likely drug users (Berger, 2006).

Another movement that intersected the HIV/AIDS epidemic was the women’s health movement in the late 1980s especially (Hubbard, 2012). ACT UP and the women’s health movement both put emphasis on the need for safe sex and sex education in schools. In pushing for these safe sex programs, they wanted the use of condoms in all sexual encounters. This along with teaching sex education in schools helped reduce the spread of AIDS. Safe sex and condom usage was not a popular platform with conservatives as they wanted a more conservative view of absence and a heteronormative view of sex (Witcher, 2019). Phyllis Schlafly, a member of a conservative group, claimed that “the ‘homosexual movement’ had ‘a well-funded educational program in the schools to present homosexuality to school children as an ‘alternative normal lifestyle’” (Witcher, 2019). This however was disproven as Reagan’s Surgeon General C. Everett Koop stated in a report that “sex education in the schools and the use of condoms [helped] to avoid AIDS” (Witcher, 2019). This statement by the US Surgeon General brought to the public what ACT UP had been preaching for years: safe sex was an important and effective way to help control the transmission of HIV/AIDS.

The HIV/AIDS crisis also intersected with homelessness and housing insecurity. In 2006 the National Alliance to End Homelessness reported that HIV/AIDS was more prevalent among those who are homeless when compared to the US general population (Julie Hilvers et al., 2016). In the 1990s, the US federal government created the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. This act was managed by the Department of Health and Human Services and allowed for resources to be allocated to state and local government to fund services for those who lived with HIV/AIDS. This included housing, transportation, treatment, and other support services of those with HIV/AIDS. Sixty-seven percent of those who received

help from the Ryan White CARE Act had household incomes at or below the US poverty line. This was in part due to the fact that while the Ryan White CARE Act provided funding for housing it was temporary, not long term support (Julie Hilvers et al., 2016). At the 2012 International AIDS Conference in Washington DC, an executive from the National AIDS Housing Coalition stated, “Housing remains the most critical need of people with HIV/AIDS living in the United States” (Julie Hilvers et al., 2016). The advances in pharmacology and the adherence to safe sex practices have helped to drive down infection rates, but homelessness could also mitigate some of these advances as homeless/housing insecurity has been linked to less adherence with medical care (Julie Hilvers et al., 2016; Wright et al., 2016). Homelessness and housing insecurity became even more of an issue when the people with HIV/AIDS were parts of marginalized groups who already faced health disparities before being diagnosed with HIV/AIDS (Wright et al., 2016).

ACT UP has made significant progress from where it started in 1987. While most chapters began to dissolve in the late 1990s, their impact has been long-lasting in the fight against HIV/AIDS. In the past 30 years, HIV/AIDS has changed from being a death sentence as a fatal disease, to a chronic illness that is manageable with medications (Wright et al., 2016). With this shift the number of deaths has decreased significantly (Wright et al., 2016). However, all of this progress has not been permanent. In 2016 when President Trump was elected, he vowed to reverse President Obama’s Affordable Care Act which contained measures that helped to support the HIV/AIDS community. On the day of President Trump’s inauguration in 2017 the pages for the Office of National AIDS policy and the National HIV/AIDS Strategy were removed from the White House website (Royles, 2020). This action reinforced the idea that constant improvement and support is necessary for people with HIV/AIDS to be treated as equal to everyone else. This action by the Presidential administration illustrated that there is further work to be done for widespread community support and acceptance. Better scientific understanding of AIDS has helped treatment progress; however, it has not removed the realities

that many face due to the associated comorbidities of AIDS. There is still much further to go in addressing the comorbidities of those with AIDS such as mental illnesses, drug use, and poverty (Wright et al., 2016). One thing that ACT UP believed in that has also yet to be achieved is the belief in “healthcare as a human right” (Hubbard, 2012). There is more work to be done on this front in the United States however, this idea is beginning to sound less “pie in the sky” especially with the realities of the COVID-19 pandemic being the center of media coverage in 2020.

Progress has been made in terms of the treatment of those with AIDS and they are less marginalized than they were in the early 1980s. This is especially true as the LGBT community has more support now than they did in the 1980s, and topics of sex are no longer as taboo as they had been. ACT UP was a group that was formed with very big goals and very little fear as they felt they had very little to lose. They utilized civil disobedience in a strategized way and figured out how to use the media to push their own message rather than the message of their opponents. While many of their protests were extremely controversial, they were able to get results in a way that no other movement had at that time. ACT UP was able to break through the ‘red tape’ at both the FDA and the NIH, while exerting influence with the Centers of Disease Control to change the definition of AIDS to help more than just males. HIV/AIDS had many victims in the late 1980s through the 1990s, however ACT UP made sure that those who died would not be forgotten and that those who had HIV/AIDS could fight to the best the best fight possible.

## Resources

*ACT UP NY | End AIDS!* (1987, 2020). <https://actupny.com>

Aizenman, N. (2019, February 9). How To Demand A Medical Breakthrough: Lessons From The AIDS Fight. *National Public Radio*. <https://www.npr.org/sections/health-shots/2019/02/09/689924838/how-to-demand-a-medical-breakthrough-lessons-from-the-aids-fight>

Berger, M. T. (2006). Narratives of Injustice. In *Workable Sisterhood*. Princeton University Press. <https://press.princeton.edu/books/paperback/9780691127705/workable-sisterhood>

Foster, P. P., & Gaskins, S. W. (2013). HIV/AIDS-Related Stigma Among African Americans in the Southern United States. In P. Liamputtong (Ed.), *Stigma, Discrimination and Living with HIV/AIDS: A Cross-Cultural Perspective* (pp. 325–336). Springer Netherlands. [https://doi.org/10.1007/978-94-007-6324-1\\_19](https://doi.org/10.1007/978-94-007-6324-1_19)

Hubbard, J. (2012). *UNITED IN ANGER | A History of ACT UP by Jim Hubbard* [YouTube]. <http://www.unitedinanger.com>

Julie Hilvers, George, C. C., & Bendixen, A. V. (2016). Chapter 11 HIV Housing Helps End Homelessness and HIV/AIDS in the United States. In *UNderstanding the HIV/AIDS Epidemic in the United States* (pp. 277–295). Springer International Publishing. DOI 10.1007/978-3-319-34004-3\_11

McClintock, K. A. (2017). The AIDS Epidemic. In *My Father's Closet* (pp. 200–204). Ohio State University Press; JSTOR. <https://doi.org/10.2307/j.ctvzxxb6p.34>

REED, T. V. (2019). ACTING UP AGAINST AIDS: THE (VERY) GRAPHIC ARTS IN A MOMENT OF CRISIS. In *The Art of Protest* (pp. 197–238). University of Minnesota Press; JSTOR. <http://www.jstor.org/stable/10.5749/j.ctvb1hrf.10>

Royles, D. (2020). Conclusion: Generations of Activism. In *The African American Struggle against HIV/AIDS* (pp. 223–226). University of North Carolina Press.

Witcher, M. M. (2019). AIDS, the New Right, and Reagan's Response. In *Getting Right with Reagan* (pp. 70–82). University Press of Kansas; JSTOR. <https://doi.org/10.2307/j.ctvx8b7f4.9>

Wright, E. R., Carnes, N., & Colón-Díaz, M. (2016). Understanding the HIV/AIDS Epidemic in the United States—The Role of Syndemics in Shaping the Public's Health. In E. R.

Wright & N. Carnes (Eds.), *Understanding the HIV/AIDS Epidemic in the United States: The Role of Syndemics in the Production of Health Disparities* (pp. 1–17). Springer International Publishing. [https://doi.org/10.1007/978-3-319-34004-3\\_1](https://doi.org/10.1007/978-3-319-34004-3_1)