

In 1981, a new disease appeared in the United States. Reactions to the disease, soon named AIDS (acquired immune deficiency syndrome), varied. Early responders cared for the sick, fought homophobia, and promoted new practices to keep people healthy. Scientists and public health officials struggled to understand the disease and how it spread. Politicians remained largely silent until the epidemic became too big to ignore. Activists demanded that people with AIDS be part of the solution.

The title *Surviving and Thriving* comes from a book written in 1987 by and for people with AIDS that insisted people could live with AIDS, not just die from it. This exhibition presents their stories alongside those of others involved in the national AIDS crisis.



Protest over Food and Drug Administration ban on Haitian blood donations, Brooklyn, New York, April 20, 1990
COURTESY AP/GERALD HERBERT

In the early 1980s, particular types of people were blamed for the spread of AIDS. The theory of the 4 H's—that AIDS was restricted to homosexuals, Haitians, hemophiliacs, and heroin users—inaccurately assumed that identity, not behavior, put people at risk.

AFFECTION IS OUR BEST PROTECTION

Gay men and lesbians were the first to respond to the growing AIDS epidemic of the early 1980s, providing care for and information to those who desperately needed it. Working to counter inaction by governmental entities, activists insisted that the fight against AIDS required eliminating fear of gays and lesbians and disseminating new ideas about sexual health.



If you *really* love him...

Rubbers – Every Time!

“If you *really* love him. . . Rubbers – Every Time!” poster, Black Gay and Lesbian Leadership Forum, Los Angeles, 1985

COURTESY NATIONAL LIBRARY OF MEDICINE

In response to a pervasive myth that AIDS was a white gay disease, black gay and lesbian organizations created campaigns targeting black men who had sex with men. They encouraged men to protect one another, insisting that love—although not in the form of marriage or even commitment—and condoms were critical for AIDS prevention.



Michael Callen (at typewriter) and Richard Berkowitz, 1984

COURTESY RICHARD DWORKIN

In 1982, Michael Callen and Richard Berkowitz, two gay men with AIDS living in New York, invented the practice of safer sex, forever changing the way people dealt with and prevented AIDS.



President Ronald Reagan (right) and Dr. C. Everett Koop at White House, circa, 1983

COURTESY NATIONAL LIBRARY OF MEDICINE

President Ronald Reagan took five years to publicly address the epidemic. At the end of 1985, he asked Surgeon General C. Everett Koop to write a “special report on AIDS.” As the “nation’s doctor,” Surgeon General Koop spearheaded a position on care, treatment, and prevention that recommended the use of condoms and “fighting a disease, not people.” Other presidential advisors advocated that all federally funded HIV/AIDS prevention material “encourage responsible sexual behavior—based on fidelity, commitment, and maturity, placing sexuality within the context of marriage.”

GOVERNMENT (IN) ACTION

The United States government remained largely silent in the face of the AIDS crisis. Elected leaders avoided the issue. Funding requests for research and patient care went unfulfilled. Fear and misinformation permeated communications. Officials blamed and stigmatized people with AIDS. Change came slowly to those with responsibility. Finally, ten years into the epidemic, Congress passed comprehensive legislation to improve the care of low-income and underinsured people with AIDS.

President Obama, with Jeanne White Ginder (right of desk) and other officials, signs the Ryan White HIV/AIDS Treatment Extension Act of 2009

COURTESY AP/GERALD HERBERT

On October 30, 2009, Barack Obama became the third president to extend the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990. Originally signed by George H. W. Bush, the act sought to improve the care of low-income and underinsured people with AIDS, policies that were all but impossible in the 1980s.



FIGHT BACK, FIGHT AIDS

By 1987, more than 46,000 Americans had become infected with HIV and more than 13,000 had died from AIDS. In response to this devastation, a new movement emerged led by people with AIDS: the AIDS Coalition to Unleash Power (ACT UP). They fought to be included in the scientific process, demanded the release of new drugs, advocated for an expanded definition of the disease, and insisted that other systemic inequalities could no longer be ignored.



Members of ACT UP/Philadelphia hold a mock funeral march in front of the governor’s mansion, August 30, 2012

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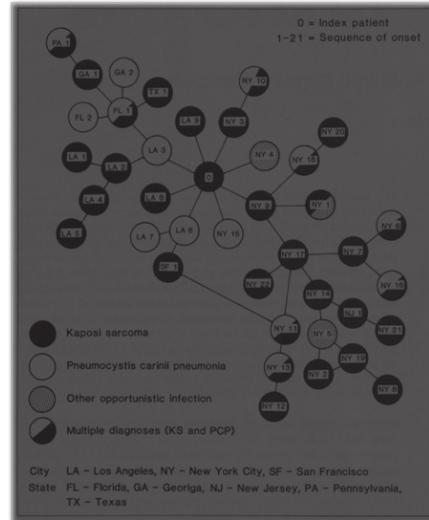
As AIDS increasingly affected people of color, gay and straight, those at the center of AIDS activism changed. In 2012, ACT UP/Philadelphia defiantly protested the state’s decision to eliminate a cash assistance program used by people living in poverty to purchase treatment medications. The chapter remains active today because it connects AIDS activism to other pressing social issues, such as access to safe housing and quality healthcare, in both the United States and around the world.

Protestors in front of the Dept. of Health and Human Services, during the national campaign to change the definition of AIDS, October 2, 1990
COURTESY DONNA BINDER

With chapters across the country, ACT UP held thousands of demonstrations between 1987 and 1996, including one at the Department of Health and Human Services to insist that women with AIDS receive care and treatment. Their actions transformed how scientists and politicians responded to the AIDS crisis.

DOING SCIENCE, MAKING MYTHS

During the mid-1980s, public health officials and scientists struggled to understand AIDS. They undertook fledgling research on shoestring budgets, conducting two distinct yet related investigations that emerged in a swirl of scientific facts and cultural myths. Some sought to determine how AIDS spread. Others tried to locate the biological agent responsible for spreading the disease. Against the backdrop of fear and misunderstanding that permeated society, scientists' initial findings sometimes produced unintended political consequences.



Map of sexual contacts among homosexual men with AIDS, from William Darrow, PhD, et al., "Cluster of Cases of the Acquired Immune Deficiency Syndrome," *American Journal of Medicine*, March 1984

COURTESY CENTERS FOR DISEASE CONTROL AND PREVENTION AND WILLIAM W. DARROW, PHD

William Darrow, a medical sociologist at the Centers for Disease Control and Prevention, drew this map to provide graphic evidence that AIDS was infectious and spread by sexual contact. After dozens of interviews and intricate data analysis, he and his collaborators presented this "cluster" of patients. Patient 0, shown in the center of the network and originally shorthand for "out-of-California," was read inaccurately as Patient Zero. In a 1987 article, *People* magazine featured Gaëtan Dugas as Patient Zero, incorrectly blaming him for infecting America with AIDS.

Robert C. Gallo, MD, at the National Institutes of Health, early 1980s

COURTESY NATIONAL CANCER INSTITUTE, NATIONAL INSTITUTES OF HEALTH

In April 1984, Dr. Robert Gallo of the National Cancer Institute at NIH isolated HTLV-III (human T-lymphotropic virus III) as the cause of AIDS. Scientists later determined it was the same virus identified as LAV (lymphadenopathy-associated virus) by Dr. Luc Montagnier and his team at the Pasteur Institute a year earlier. Despite disagreement over who made the initial discovery, French and American researchers eventually agreed to share the credit. In 1986, the virus was renamed HIV (human immunodeficiency virus). Identifying a viral cause enabled the scientific community to develop a test for HIV and better confront AIDS with treatment.



AIDS IS NOT OVER

The challenges posed by AIDS today are complex. Treatments exist but are not uniformly available. Debates persist about what prevention strategies are politically acceptable. People with AIDS and their advocates have made lasting changes to contain the epidemic and provide access to lifesaving treatments, but serious obstacles—including poverty and societal violence—preclude many from staying healthy. Dedicated health professionals continue to work alongside longtime activists. Together, they struggle to develop new ways to care for people living with HIV/AIDS and prevent the disease from spreading.



View of New York City subway car depicting part of the *La Decisión* serialized story, April 6, 1993 (Above) and *La Decisión I*, New York City Department of Health, 1990 (Below)

COURTESY AP/PAUL HURSCHMANN (ABOVE) AND NATIONAL LIBRARY OF MEDICINE (BELOW)

Produced by the New York City Department of Health and funded by the federal government to reach Spanish- and English-speaking subway riders, this comic ran for more than a decade and on more than six thousand train cars. *La Decisión* serialized the story of Marisol, a Latina struggling with her boyfriend, Julio, over using a condom, and watching friends die from AIDS.



"Ask for the Test" poster, 2012

COURTESY HAHSTA (HIV/AIDS, HEPATITIS, STD, TB ADMINISTRATION), DISTRICT OF COLUMBIA DEPARTMENT OF HEALTH

In the 21st century, testing for HIV is the first line of defense in the battle against AIDS. But when the test was released in 1985, many people refused for fear that their names would go on a registry to deny them health care. Municipal unions in Washington, DC, are at the forefront of fighting this persistent myth and explaining how testing helps keep people healthy.



SURVIVING & THRIVING

AIDS, POLITICS, AND CULTURE

"We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS.'"

Denver Principles, 1983



People with AIDS group, Denver, June 1983
COURTESY @JOHN SCHOENWALTER

First carried at candlelight vigils in San Francisco to call attention to the experiences of people with AIDS, this banner made its way to Denver for the Fifth National Lesbian and Gay Health Conference. Once in Colorado, the men pictured wrote the Denver Principles, a document that fundamentally shifted the debate about how to treat people with AIDS. Together, the sign and the manifesto animated the movement led by people with AIDS.



This exhibition was produced by the National Library of Medicine, National Institutes of Health. Curated by Jennifer Brier, PhD. Exhibition design by Riggs Ward Design. www.nlm.nih.gov/survivingandthriving