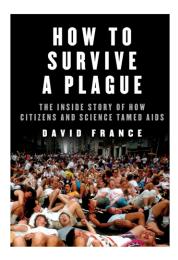
Activism Combatting AIDS



How to Survive a Plague: The Inside Story of How Citizens and Science Tamed AIDS By David France

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See also Morabia, p. 1203.

I read *How to Survive a Plague* by David France twice before attempting to write a review. The book is remarkable and extraordinarily well written, but also as painful to read as it is compelling. This critical inside history of the AIDS epidemic is both richly personal and detailed; it focuses on the suffering and accomplishments of those in the gay community, but it sometimes neglects other perspectives.

A TURNING POINT

Where were you in 1981, and when did you first learn of AIDS? For many of us old enough to remember and who were engaged in the answer to these questions, 1981 marks a personal as well as professional turning point. The first report in June 1981 was of five cases of Pneumocystis carinii pneumonia (PCP) among previously healthy homosexual men from Los Angeles¹ with cases soon reported of PCP and Kaposi's sarcoma among gay men in New York City.² In June 1981, I first visited New York on behalf of the Centers for Disease Control and Prevention (CDC) to examine a man with Kaposi's sarcoma at New York University Medical Center. He was the first patient I had ever encountered with Kaposi's sarcoma or what would become known as AIDS. That trip was the first of 40 that I made to New York City that first year.

In June 1981, David France, a recent college graduate from Michigan, moved to New York to seek a career in writing and journalism and to live where he could be himself as an openly gay man.

The same year, Ronald Reagan had been inaugurated as the 40th President of the United States. The 1970s had been described as witnessing a sexual revolution in the United States, with skyrocketing rates of sexually transmitted infections among heterosexual men and women, as well as gay men. It had been a mere dozen years since gay liberation was punctuated by police raids and subsequent demonstrations near the Stonewall Bar in Greenwich Village.

AN OPENLY GAY JOURNALIST

Thus begins David France's compelling inside story of facing the emergence of an overwhelming plague and the misery of AIDS in New York City over the next decade and a half. France lived the epidemic in New York City as a young gay

man, and he chronicled it as a journalist, first with the New York Native, but also with other publications including, briefly, the New York Post. In the early 1980s, being an openly gay journalist and covering AIDS for a major mainstream publication was extremely rare. The late Randy Shilts, reporter for the San Francisco Chronicle and author of And the Band Played On, claimed to be the only openly gay mainstream journalist in the United States during that time period. However, reporters for the New York Native, including France and Lawrence Mass, produced some of the most accurate and timely information on the subject in the 1980s. This richly detailed and nuanced history is the result of France's personal and journalistic involvement in AIDS during this period.

The book begins with the first cases of PCP and Kaposi's sarcoma in gay men in New York City. Much of the gay community in New York City was in denial while the mainstream media and most others ignored the problem. In addition to the New York Native staff, one of those sounding the alarm was Larry Kramer, cofounder of the Gay Men's Health Crisis (GMHC), the nation's first nongovernmental organization solely dedicated to AIDS. Larry's stridency soon placed him at odds with the organization he founded when he

ABOUT THE AUTHOR

James W. Curran is with the Rollins School of Public Health, Emory University, and Emory Center for AIDS Research, Atlanta, GA.

Correspondence should be sent to James W. Curran, MD, MPH, Rollins School of Public Health, Emory University, 1518 Clifton Road, Room 8011, Atlanta, GA 30322 (e-mail: jcurran@emory.edu). Reprints can be ordered at http://www.ajph.org by clicking the "Reprints" link

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published a piece in the GMHC Newsletter as follows:

We have been too accustomed to fear, particularly the fear that our sexual freedom, so hard fought for, will be taken away from us. But we must realize that sex is not the fabric holding our community together. . . . And if it takes an emergency epidemic to teach us this lesson, then let this be one of life's ironies. (p80–81)

PORTRAYALS

Throughout the book, France describes the crucial but controversial roles that Kramer continued to play in activism from the publication of the *Normal Heart* to the founding of ACT-UP and beyond. Over the years, Kramer aroused emotions, faded from the scene, and then reappeared to sound a warning against complacency and inaction.

France vividly portrays the suffering of countless friends who were ill during the plague years, as well as the effect it had on others. AIDS in the New York community was visible and palpable during the 1980s, and many persons were isolated and alone in their suffering. He describes the case of a Puerto Rican man named Juan living in his apartment building. His wife banished him from his apartment because of his drug use and AIDS. France saw him in the hallway, heartbroken:

"Are you alright Juan?" His (Juan's) voice was hollow and raspy, the unmistakable sound of PCP. "At the VA, they told me to go home to Puerto Rico to die, but how?" A sudden pain contorted his face. He gripped his abdomen and gave a look of terrified foreknowledge. But there was no time—his bowels emptied with terrible force, painting a mandala of excrement on

the floor where he sat. I pounded on the door of his apartment. . . . (But) on fragile legs (he) carried his shame down to the street. He need not have fled; his wife never came to the door. $(p^{217-218})$

BOLD ACTIVISTS

Much of this book provides details about the people and processes of activism, led by the gay community, which had such great impact on the response. The courageous actions by activists, many HIV-infected themselves, forced dialogue and action with the National Institutes of Health (NIH), the Food and Drug Administration (FDA), CDC, and pharmaceutical companies. These confrontations and deliberations are vividly described from the testing of failed drugs to the breakthrough of azidothymidine, other antiretrovirals, and the combination therapy that eventually successfully saved the lives of millions. The activists were bold and became highly informed. They demanded priority from the NIH for access to deliberations on clinical trial priorities to include opportunistic infections, faster approval, and a parallel track from the FDA for new drugs, as well as more transparency and lower prices from the pharmaceutical companies. France provides fascinating details of the many meetings and demonstrations as well as that of the people themselves, including his views of the government, industry, and academic protagonists. The in-fighting among the activists is described as well. In the end, the activism provided great focus and attention to aid the scientific breakthroughs.

In my view, this history provides insufficient appreciation for

the scientists, physicians, and government officials who toiled mightily and contributed to the current successes. Some, like Ellen Cooper and Anthony Fauci, were working inside at the nexus of science and politics, and fighting equally as hard as the activists. They and others are unfairly criticized in this book, and their perspective must be told by others.

LESSONS ABOUT COURAGE

How to Survive a Plague tells of the widespread suffering, which will make you angry or even cry, but the courage shown by the community to partner with scientists and caregivers to reach the successes in HIV therapy is redeeming. Thus, France's description of his own reaction at hearing a presentation at New York University on the early results of highly active antiretroviral therapy (HAART) shows:

(The doctor) "We think these drugs . . . might allow people to lead a normal life". (France) It had been many years since I cried—but now tears rolled down my cheeks. . . . Was it over? Was the long nightmare passed? . . . I was thirty-five years old. I've lived my entire adult life in the age of unrelenting death. We all had. The feeling of relief overwhelmed me. (p508–509)

By then, hundreds of thousands of Americans and millions throughout the world had died of AIDS. The historical perspective from the gay community in New York is an invaluable lesson about the courage and burdens of the survivors, as well as those whose lives were prematurely lost.

How to Survive a Plague is a must-read for those interested

in AIDS, public health, or community advocacy and activism. We survivors must partner with new colleagues to focus on HIV research and prevention and on care for the 40 million HIV-positive citizens of the world.

AJPH

James W. Curran, MD, MPH

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