

AND THE BAND PLAYED ON

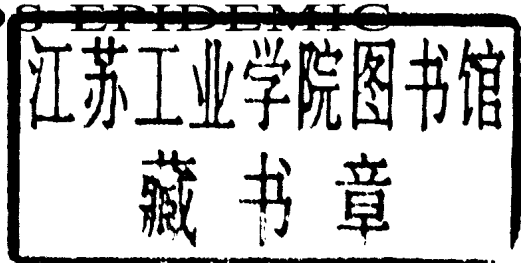
POLITICS, PEOPLE, AND THE
AIDS EPIDEMIC



RANDY SHILTS

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QUALITY PAPERBACK BOOK CLUB
NEW YORK

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Printed in the United States of America

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PLAYED ON**

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For Ann Neuenschwander

ACKNOWLEDGMENTS

I would not have been able to write this book if I had not been a reporter at the *San Francisco Chronicle*, the only daily newspaper in the United States that did not need a movie star to come down with AIDS before it considered the epidemic a legitimate news story deserving thorough coverage. Because of the *Chronicle's* enlightened stance, I have had free rein to cover this epidemic since 1982; since 1983, I have spent virtually all my time reporting on AIDS. My reporting provided the core of this book. While this newspaper's commitment is a credit to all levels of *Chronicle* management, I particularly want to thank my city editor, Alan Mutter, who believed in the value of this story long before it was fashionable. I'm also grateful to the following *Chronicle* colleagues for their guidance and assistance: Katy Butler, David Perlman, Jerry Burns, Keith Power, and Kathy Finberg. The *Chronicle's* library staff, especially Charlie Malarkey, also helped immensely.

My newspaper reporting would never have been transformed into a book if it were not for the faith of my editor at St. Martin's Press, Michael Denny. He believed in this project when most in publishing doubted that the epidemic would ever prove serious enough to warrant a major book. I'm also grateful to the confidence of my agent, Fred Hill.

A number of other people helped me edit the manuscript. Without the constant encouragement, hand-holding, and insightful editing of Doris Ober, I could never have made it to the end of what became a very long tome. I'm also grateful to Katie Leishman and Rex Adkins for devoting their extraordinary editing talents to the manuscript.

The research phase of the book required much travel and would not have been tolerable without hosts such as Poul Birch Eriksen in Copenhagen, Mark Pinney in New York City, and Bob Canning and Steve Sansweet in Los Angeles. I'm also thankful to Frank Robinson, who kept voluminous files on the epidemic and generously shared them all with me. Among the other people who charitably opened their files to me were Tim Westmoreland, Dan Turner, David Nimmons, Jeff Richardson, Lawrence Schulman, Tom Murray of *The Sentinel*, Don Michaels of the *Washington Blade*, Terry Biern of the American Foundation for AIDS Research, and Jim Kepner of the AIDS History Project at the International Gay and Lesbian Archives in Los Angeles. Steve Unger and Fred Hoffman provided expert computer assistance. I would be remiss if I

didn't acknowledge the help I got from the media relations staffs of San Francisco General Hospital, Pasteur Institute, National Cancer Institute, National Institute for Allergy and Infectious Diseases, and especially Chuck Fallis at the Centers for Disease Control. They made my job much easier.

I remain indebted to my brothers Reed Shilts, Russell Dennis Shilts III, and Gary Shilts for their support during the long writing process. I'm also blessed by some terrific friends who stuck by me during the insanity of this project: Janie Krohn, Bill Reiner, David Israels, Bill Cagle, Will Pretty, and Rich Shortell. Thanks also to the friends of Bill W. who sustained me with their experience, strength, and hope.

Ultimately, a reporter is only as good as his sources. The people to whom I remain most grateful are the hundreds who shared their time with me both during my newspaper reporting and during the book research. Many were scientists and doctors who carved large blocks of time out of hectic schedules. My deep background and off-the-record sources were also invaluable; you know who you are, and I thank you.

The people for whom I will always bear special reverence are those who were suffering from AIDS and who gave some of their last hours for interviews, sometimes while they were on their deathbeds laboring for breath. When I'd ask why they'd take the time for this, most hoped that something they said would save someone else from suffering. If there is an act that better defines heroism, I have not seen it.

DRAMATIS PERSONAE

DR. FRANCOISE BARRE, a researcher with the Pasteur Institute, the first to isolate the AIDS virus.

DR. BOB BIGGAR, a researcher with the Environmental Epidemiology branch of the National Cancer Institute.

FRANCES BORCHELT, a San Francisco grandmother.

DR. EDWARD BRANDT, Assistant Secretary for Health of the U.S. Department of Health and Human Services.

JOE BREWER, a gay psychotherapist in San Francisco's Castro Street neighborhood.

HARRY BRITT, the only openly gay member of San Francisco's board of supervisors, the local equivalent of a city council.

U.S. REPRESENTATIVE PHILIP BURTON, a staunch liberal who represented San Francisco in Congress.

U.S. REPRESENTATIVE SALA BURTON succeeded her husband in Congress.

MICHAEL CALLEN, a rock singer who organized the People With AIDS Coalition in New York City.

LU CHAIKIN, a lesbian psychotherapist in San Francisco's Castro Street neighborhood.

DR. JEAN-CLAUDE CHERMANN, part of the Pasteur Institute team that first isolated the AIDS virus.

DR. MARCUS CONANT, a dermatologist affiliated with the University of California at San Francisco.

DR. JAMES CURRAN, an epidemiologist and director of AIDS research efforts at the U.S. Centers for Disease Control in Atlanta.

WILLIAM DARROW, a sociologist and epidemiologist involved with AIDS research at the Centers for Disease Control.

DR. WALTER DOWDLE, director of the Center for Infectious Diseases.

DR. SELMA DRITZ, assistant director of the Bureau of Communicable Disease Control at the San Francisco Department of Public Health.

GAETAN DUGAS, a French-Canadian airline steward for Air Canada, one of the first North Americans diagnosed with AIDS.

DR. MYRON "MAX" ESSEX, a retrovirologist with Harvard University School of Public Health.

SANDRA FORD, a drug technician at the Centers for Disease Control.

DR. WILLIAM FOEGE, director of the Centers for Disease Control during the first years of the AIDS epidemic.

DR. DONALD FRANCIS, a retrovirologist who directed laboratory efforts for AIDS research at the Centers for Disease Control.

DR. ROBERT GALLO, a retrovirologist with the National Cancer Institute in Bethesda.

DR. MICHAEL GOTTLIEB, an immunologist with the University of California at Los Angeles.

ENRIQUE "KICO" GOVANTES, a gay San Francisco artist, lover of Bill Kraus.

DR. JAMES GROUNDWATER, a dermatologist who treated San Francisco's first reported AIDS case.

DR. MARY GUINAN, an epidemiologist involved with early AIDS research at the Centers for Disease Control.

MARGARET HECKLER, Secretary of the U.S. Department of Health and Human Services from early 1983 through the end of 1985.

KEN HORNE, the first reported AIDS case in San Francisco.

DR. HAROLD JAFFE, an epidemiologist with the AIDS program at the Centers for Disease Control.

CLEVE JONES, a San Francisco gay activist, organizer of the Kaposi's Sarcoma Research and Education Foundation.

LARRY KRAMER, novelist, playwright, and film producer, organizer of Gay Men's Health Crisis in New York City.

BILL KRAUS, prominent San Francisco gay leader, aide to U.S. Reps. Philip and Sala Burton.

MATTHEW KRIEGER, a San Francisco graphic designer, lover of Gary Walsh.

DR. MATHILDE KRIM, socially prominent cancer researcher, organized the AIDS Medical Foundation.

DR. DALE LAWRENCE, conducted early studies of AIDS in hemophiliacs and blood transfusion recipients for the Centers for Disease Control.

MICHAEL MALETTA, hair dresser who was one of San Francisco's early AIDS cases.

DR. JAMES MASON, director of the Centers for Disease Control since late 1983, served as acting Assistant Secretary for Health in 1985.

RODGER MCFARLANE, executive director of the Gay Men's Health Crisis in New York City.

DR. DONNA MILDVAN, AIDS researcher at Beth Israel Medical Center in Manhattan.

DR. LUC MONTAGNIER, head of the Pasteur Institute team that first isolated the AIDS virus.

JACK NAU, one of New York City's early AIDS cases, a former lover of Paul Popham.

ENNO POERSCH, a graphic designer drawn into AIDS organizing because of the death of his lover, Nick, in early 1981.

PAUL POPHAM, Wall Street businessman, president of Gay Men's Health Crisis.

DR. GRETHE RASK, Danish surgeon in Zaire, first westerner documented to have died of AIDS.

DR. WILLY ROZENBAUM, leading AIDS clinician in Paris.

DR. ARYE RUBINSTEIN, immunologist in the Bronx, among the first to detect AIDS in infants.

DR. DAVID SENCER, health commissioner of New York City.

DR. MERVYN SILVERMAN, director of the San Francisco Department of Public Health.

DR. PAUL VOLBERDING, director of the San Francisco General Hospital AIDS Clinic.

GARY WALSH, a San Francisco gay psychotherapist, early organizer of AIDS sufferers.

DRAMATIS PERSONAE

U.S. REPRESENTATIVE HENRY WAXMAN of Los Angeles, chair of House Subcommittee on Health and the Environment.

DR. JOEL WEISMAN, a prominent gay physician in Los Angeles, among the first to detect the AIDS epidemic.

RICK WELLIKOFF, a Brooklyn schoolteacher who was among the nation's first AIDS cases, close friend of Paul Popham.

TIM WESTMORELAND, counsel to the House Subcommittee on Health and the Environment.

DR. DAN WILLIAM, a prominent gay physician in New York City.

PROLOGUE

By October 2, 1985, the morning Rock Hudson died, the word was familiar to almost every household in the Western world.

AIDS.

Acquired Immune Deficiency Syndrome had seemed a comfortably distant threat to most of those who had heard of it before, the misfortune of people who fit into rather distinct classes of outcasts and social pariahs. But suddenly, in the summer of 1985, when a movie star was diagnosed with the disease and the newspapers couldn't stop talking about it, the AIDS epidemic became palpable and the threat loomed everywhere.

Suddenly there were children with AIDS who wanted to go to school, laborers with AIDS who wanted to work, and researchers who wanted funding, and there was a threat to the nation's public health that could no longer be ignored. Most significantly, there were the first glimmers of awareness that the future would always contain this strange new word. AIDS would become a part of American culture and indelibly change the course of our lives.

The implications would not be fleshed out for another few years, but on that October day in 1985 the first awareness existed just the same. Rock Hudson riveted America's attention upon this deadly new threat for the first time, and his diagnosis became a demarcation that would separate the history of America before AIDS from the history that came after.

The timing of this awareness, however, reflected the unalterable tragedy at the heart of the AIDS epidemic: By the time America paid attention to the disease, it was too late to do anything about it. The virus was already pandemic in the nation, having spread to every corner of the North American continent. The tide of death that would later sweep America could, perhaps, be slowed, but it could not be stopped.

The AIDS epidemic, of course, did not arise full grown from the biological landscape; the problem had been festering throughout the decade. The death tolls of the late 1980s are not startling new developments but an unfolding of events predicted for many years. There had been a time when much of this suffering could have been prevented, but by 1985 that time had passed. Indeed, on the day the world learned that Rock Hudson was stricken, some 12,000 Americans were already dead or dying of AIDS and hundreds of thousands more were infected with

the virus that caused the disease. But few had paid any attention to this; nobody, it seemed, had cared about them.

The bitter truth was that AIDS did not just happen to America—it was allowed to happen by an array of institutions, all of which failed to perform their appropriate tasks to safeguard the public health. This failure of the system leaves a legacy of unnecessary suffering that will haunt the Western world for decades to come.

There was no excuse, in this country and in this time, for the spread of a deadly new epidemic. For this was a time in which the United States boasted the world's most sophisticated medicine and the world's most extensive public health system, geared to eliminate such pestilence from our national life. When the virus appeared, the world's richest nation housed the most lavishly financed scientific research establishments—both inside the vast governmental health bureaucracy and in other institutions—to investigate new diseases and quickly bring them under control. And making sure that government researchers and public health agencies did their jobs were the world's most unfettered and aggressive media, the public's watchdogs. Beyond that, the group most affected by the epidemic, the gay community, had by then built a substantial political infrastructure, particularly in cities where the disease struck first and most virulently. Leaders were in place to monitor the gay community's health and survival interests.

But from 1980, when the first isolated gay men began falling ill from strange and exotic ailments, nearly five years passed before all these institutions—medicine, public health, the federal and private scientific research establishments, the mass media, and the gay community's leadership—mobilized the way they should in a time of threat. The story of these first five years of AIDS in America is a drama of national failure, played out against a backdrop of needless death.

People died while Reagan administration officials ignored pleas from government scientists and did not allocate adequate funding for AIDS research until the epidemic had already spread throughout the country.

People died while scientists did not at first devote appropriate attention to the epidemic because they perceived little prestige to be gained in studying a homosexual affliction. Even after this denial faded, people died while some scientists, most notably those in the employ of the United States government, competed rather than collaborated in international research efforts, and so diverted attention and energy away from the central struggle against the disease itself.

People died while public health authorities and the political leaders who guided them refused to take the tough measures necessary to curb the epidemic's spread, opting for political expediency over the public health.

And people died while gay community leaders played politics with the disease, putting political dogma ahead of the preservation of human life.

People died and nobody paid attention because the mass media did

not like covering stories about homosexuals and was especially skittish about stories that involved gay sexuality. Newspapers and television largely avoided discussion of the disease until the death toll was too high to ignore and the casualties were no longer just the outcasts. Without the media to fulfill its role as public guardian, everyone else was left to deal—and not deal—with AIDS as they saw fit.

In those early years, the federal government viewed AIDS as a budget problem, local public health officials saw it as a political problem, gay leaders considered AIDS a public relations problem, and the news media regarded it as a homosexual problem that wouldn't interest anybody else. Consequently, few confronted AIDS for what it was, a profoundly threatening medical crisis.

Fighting against this institutional indifference were a handful of heroes from disparate callings. Isolated teams of scientists in research centers in America and Europe risked their reputations and often their jobs to pioneer early research on AIDS. There were doctors and nurses who went far beyond the call of duty to care for its victims. Some public health officials struggled valiantly to have the epidemic addressed in earnest. A handful of gay leaders withstood vilification to argue forcefully for a sane community response to the epidemic and to lobby for the funds that provided the first breakthroughs in research. And there were many victims of the epidemic who fought rejection, fear, isolation, and their own deadly prognoses to make people understand and to make people care.

Because of their efforts, the story of politics, people, and the AIDS epidemic is, ultimately, a tale of courage as well as cowardice, compassion as well as bigotry, inspiration as well as venality, and redemption as well as despair.

It is a tale that bears telling, so that it will never happen again, to any people, anywhere.

THE BUREAUCRACY

In the government of the United States, health agencies are part of the U.S. Department of Health and Human Services (HHS). Most of the key health and scientific research agencies fall under the umbrella of the U.S. Public Health Service (PHS), which is directed by the Assistant Secretary for Health of the Department of Health and Human Services. The National Institutes of Health (NIH), Food and Drug Administration (FDA), and Centers for Disease Control (CDC) are among the agencies that comprise the PHS.

The National Institutes of Health is comprised of various separate institutes that conduct most of the government's laboratory research into health matters. Two of the largest institutes at the NIH are also the two that were most involved in AIDS research, the National Cancer Institute (NCI) and the National Institute of Allergy and Infectious Diseases (NIAID).

The Centers for Disease Control is comprised of different centers that handle various public health problems. The largest is the Center for Infectious Diseases, under which AIDS research has been handled through most of the epidemic. The Kaposi Sarcoma-Opportunistic Infections Task Force (KSOI Task Force), which changed its name to the AIDS Task Force, and later to the AIDS Activities Office, was part of the CID.

The Kaposi's Sarcoma Research and Education Foundation (KS Foundation) was organized in San Francisco in early 1982. In 1983, it split into the National Kaposi's Sarcoma/AIDS Research and Education Foundation (National KS Foundation), which dissolved in 1984, and the San Francisco Kaposi's Sarcoma/AIDS Research Foundation. The latter group subsequently changed its name to the San Francisco AIDS Foundation.

The AIDS Medical Foundation was organized in New York City in 1983. In 1985, it merged with the National AIDS Research Foundation to become the American Foundation for AIDS Research (AmFAR).

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