PRAISE FOR AND THE BAND PLAYED ON

‘A prescient analysis of the harm wrought when public health is not a financial priority … [Shilts’s] clear-eyed, nuanced portrait of the gay community made him a champion to many’ Best 100 Non-Fiction Books of All Time, TIME

‘Rivals in power and intensity, and in the brilliance of its reporting and writing, Truman Capote’s In Cold Blood’ Boston Globe

‘The book conveys in detail the political complexities – and many different human dimensions – of the story … Shilts has produced the best – and what will likely be the most controversial – book yet on AIDS. Though many of the details in the book are familiar to veteran reporters, Shilts does not shy away from naming names and casting blame. He writes with passionate conviction’ Newsweek

‘Shilts, a reporter for the San Francisco Chronicle who has covered AIDS full-time since 1983, takes us almost day by day through the first five years of the unfolding epidemic and the responses – confusion and fear, denial and indifference, courage and determination. It is at once a history and a passionate indictment’ New York Times Book Review

‘Randy Shilts’s magnificent book charts the rise and rise of AIDS … It’s written like the best kind of thriller, detail upon detail, collecting clues, revealing apparently forgotten connections, documenting the assembly of evidence’ Irish Times

‘A textbook on how institutions work – or fail to work – in the face of such a threat’ San Francisco Examiner

‘A lucid and stunning indictment of public policy toward the vicious disease … A valuable work of political history’ Business Week

‘Shilts successfully weaves comprehensive investigative reporting and commercial page-turning pacing, political intrigue and personal tragedy into a landmark book … Its importance cannot be overstated’ Publishers Weekly
‘A massive, ominous, compelling book that tells the most definitive story of the AIDS crisis in America to date … knowledgeable, painful, compulsively readable’ Kirkus

‘Shilts, who has been covering the AIDS crisis since 1981, sets a gripping narrative of human tragedy against a background of political and scientific controversy … Shilts has the ability to draw the reader hypnotically into the personal lives of his characters. That, and his monumental investigative effort, would have made this a best-selling novel if the contents weren’t so horribly true’ Library Journal

‘If long reads are your thing then it’s hard to do better than And the Band Played On by Randy Shilts. Few pieces of literary journalism are as epic and as in-depth as this one … Shilts was a pioneer who helped show that journalism has no limits or boundaries’ The Queerness blog
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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.

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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.

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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).
AND
THE BAND
PLAYED ON
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.
And I looked, and behold a pale horse: and his name that sat on him was Death, and Hell followed with him. And power was given unto them over the fourth part of the earth, to kill with sword, and with hunger, and with death, and with the beasts of the earth.

—Revelation 6:8
THE FEAST OF THE HEARTS

July 4, 1976
NEW YORK HARBOR

Tall sails scraped the deep purple night as rockets burst, flared, and flourished red, white, and blue over the stoic Statue of Liberty. The whole world was watching, it seemed; the whole world was there. Ships from fifty-five nations had poured sailors into Manhattan to join the throngs, counted in the millions, who watched the greatest pyrotechnic extravaganza ever mounted, all for America’s 200th birthday party. Deep into the morning, bars all over the city were cramned with sailors. New York City had hosted the greatest party ever known, everybody agreed later. The guests had come from all over the world.

This was the part the epidemiologists would later note, when they stayed up late at night and the conversation drifted toward where it had started and when. They would remember that glorious night in New York Harbor, all those sailors, and recall: From all over the world they came to New York.

Christmas Eve, 1976
KINSHASA, ZAIRE

The hot African sky turned black and sultry; it wasn’t like Christmas at all.

The unrelenting mugginess of the equatorial capital made Dr. Ib Bygbjerg even lonelier for Denmark. In the kitchen, Dr. Grethe Rask, determined to assuage her young colleague’s homesickness, began preparing an approximation of the dinner with which Danes traditionally begin their Christmas observance, the celebration known through centuries of custom as the Feast of the Hearts.

The preparations brought back memories of the woman’s childhood in Thisted, the ancient Jutland port nestled on the Lim Fiord not far from the North Sea. As the main course, Grethe Rask knew, there needed to be something that flies. In Jutland that would mean goose or duck; in Zaire, chicken would have to suffice. As she began preparing the fowl, Grethe again felt the familiar fatigue wash over her. She had spent the last two years haunted by weariness, and by now, she knew she couldn’t fight it.
Grethe collapsed on her bed. She had been among the Danish doctors who came to replace the Belgian physicians who were no longer welcome in this new nation eager to forget its recent colonial incarnation as the Belgian Congo. Grethe had first gone there in 1964, returning to Europe for training in stomach surgery and tropical diseases. She had spent the last four years in Zaire but, despite all this time in Africa, she remained unmistakably from the Danish stock who proudly announce themselves as north of the fjord. To be north of the Lim Fiord was to be direct and decisive, independent and plainspoken. The Jutlanders born south of the stretch of water that divides the Danish peninsula tend toward weakness, as anyone north of the fjord might explain. Far from the kings in Copenhagen, these hardy northern people had nurtured their collective heritage for centuries. Grethe Rask from Thisted mirrored this.

It explained why she was here in Zaire, 5,000 miles from where she might forge a lucrative career as a surgeon in the sprawling modern hospitals of Copenhagen. Such a cosmopolitan career meant people looking over her shoulder, giving orders. Grethe preferred the work she had done at a primitive hospital in the remote village of Abumombazi in the north of Zaire. She alone was in charge there.

The hospital conditions in Abumombazi were not as deplorable as in other parts of the country. A prominent Zairian general came from the region. He had had the clout to attract a white doctor to the village, and there, with Belgian nuns, Grethe worked with what she could beg and borrow. This was Central Africa, after all, and even a favored clinic would never have such basics as sterile rubber gloves or disposable needles. You just used needles again and again until they wore out; once gloves had worn through, you risked dipping your hands in your patient’s blood because that was what needed to be done. The lack of rudimentary supplies meant that a surgeon’s work had risks that doctors in the developed world could not imagine, particularly because the undeveloped part, specifically Central Africa, seemed to sire new diseases with nightmarish regularity. Earlier that year, not far from Abumombazi, in a village along the Ebola River on the Zaire-Sudan border, a virulent outbreak of a horrifying new disease had demonstrated the dangers of primitive medicine and new viruses. A trader from the village of Enzara, suffering from fevers and profuse, uncontrollable bleeding, had come to the teaching hospital for nurses in Maridi. The man apparently had picked up the disease sexually. Within days, however, 40 percent of the student nurses in Maridi were stricken with the fever, transmitted by contact with the patient’s infected blood either through standard care procedures or through accidental needle-sticks.

Frightened African health officials swallowed their pride and called the World Health Organization, who came with a staff from the American Centers for Disease Control. By the time the young American doctors arrived, thirty-nine nurses and two doctors were dead. The CDC doctors worked quickly, isolating all patients with fevers. Natives were infuriated when the Americans banned the traditional burials of the victims since the ritual bathing of the bodies was clearly spreading the disease further. Within weeks, however, the epidemic was under control. In the end, the Ebola Fever virus, as it came to be known,
killed 53 percent of the people it infected, seizing 153 lives before it disappeared as suddenly and mysteriously as it had arisen. Sex and blood were two horribly efficient ways to spread a new virus, and years later, a tenuous relief would fill the voices of doctors who talked of how fortunate it was for human-kind that this new killer had awakened in this most remote corner of the world and had been stamped out so quickly. A site just a bit closer to regional crossroads could have unleashed a horrible plague. With modern roads and jet travel, no corner of the earth was very remote anymore; never again could diseases linger undetected for centuries among a distant people without finding some route to fan out across the planet.

The battle between humans and disease was nowhere more bitterly fought than here in the fetid equatorial climate, where heat and humidity fuel the generation of new life forms. One historian has suggested that humans, who first evolved in Africa eons ago, migrated north to Asia and Europe simply to get to climates that were less hospitable to the deadly microbes the tropics so efficiently bred.

Here, on the frontiers of the world’s harshest medical realities, Grethe Rask tended the sick. In her three years in Abumombazi, she had bullied and cajoled people for the resources to build her jungle hospital, and she was loved to the point of idolization by the local people. Then, she returned to the Danish Red Cross Hospital, the largest medical institution in the bustling city of Kinshasa, where she assumed the duties of chief surgeon. Here she met Ib Bygbjerg, who had returned from another rural outpost in the south. Bygbjerg’s thick dark hair and small compact frame belied his Danish ancestry, the legacy, he figured, of some Spanish sailor who made his way to Denmark centuries ago. Grethe Rask had the features one would expect of a woman from Thisted, high cheekbones and blond hair worn short in a cut that some dedicatedly called mannish.

To Bygbjerg’s eye, on that Christmas Eve, there were troubling things to note about Grethe’s appearance. She was thin, losing weight from a mysterious diarrhea. She had been suffering from the vague yet persistent malaise for two years now, since her time in the impoverished northern villages. In 1975, the problem had receded briefly after drug treatments, but for the past year, nothing had seemed to help. The surgeon’s weight dropped further, draining and weakening her with each passing day.

Even more alarming was the disarray in the forty-six-year-old woman’s lymphatic system, the glands that play the central role in the body’s never-ending fight to make itself immune from disease. All of Grethe’s lymph glands were swollen and had been for nearly two years. Normally, a lymph node might swell here or there to fight this or that infection, revealing a small lump on the neck, under an arm, or perhaps, in the groin. There didn’t seem to be any reason for her glands to swell; there was no precise infection anywhere, much less anything that would cause such a universal enlargement of the lymph nodes all over her body.

And the fatigue. It was the most disconcerting aspect of the surgeon’s malaise. Of course, in the best of times, this no-nonsense woman from north of the fjord did not grasp the concept of relaxation. Just that day, for example, she had not
been scheduled to work, but she put in a full shift, anyway; she was always working, and in this part of the world nobody could argue because there was always so much to be done. But the weariness, Bygbjerg could tell, was not bred by overwork. Grethe had always been remarkably healthy, throughout her arduous career. No, the fatigue was something darker; it had become a constant companion that weighted her every move, mocking the doctor's industry like the ubiquitous cackling of the hyena on the savannah.

Though she was neither sentimental nor particularly Christian, Grethe Rask had wanted to cheer her young colleague; instead, she lay motionless, paralyzed again. Two hours later, Grethe stirred and began, halfheartedly, to finish dinner. Bygbjerg was surprised that she was so sick then that she could not muster the strength to stay awake for something as special as the Feast of the Hearts.

November 1977

HJARDEMAAL, DENMARK

A cold Arctic wind blistered over the barren heath outside a whitewashed cottage that sat alone, two miles from the nearest neighbors in the desolate region of Denmark north of the Lim Fiord. Sweeping west, from the North Sea over the sand dunes and low, bowed pines, the gusts made a whoosh-whooshing sound. Inside the little house, under a neat red-tiled roof, Grethe Rask gasped her short, sparse breaths from an oxygen bottle.

"I'd better go home to die," Grethe had told Ib Bygbjerg matter-of-factly.

The only thing her doctors could agree on was the woman's terminal prognosis. All else was mystery. Also newly returned from Africa, Bygbjerg pondered the compounding mysteries of Grethe's health. None of it made sense. In early 1977, it appeared that she might be getting better; at least the swelling in her lymph nodes had gone down, even as she became more fatigued. But she had continued working, finally taking a brief vacation in South Africa in early July.

Suddenly, she could not breathe. Terrified, Grethe flew to Copenhagen, sustained on the flight by bottled oxygen. For months now, the top medical specialists of Denmark had tested and studied the surgeon. None, however, could fathom why the woman should, for no apparent reason, be dying. There was also the curious array of health problems that suddenly appeared. Her mouth became covered with yeast infections. Staph infections spread in her blood. Serum tests showed that something had gone awry in her immune system; her body lacked T-cells, the quarterbacks in the body's defensive line against disease. But biopsies showed she was not suffering from a lymph cancer that might explain not only the T-cell deficiency but her body's apparent inability to stave off infection. The doctors could only gravely tell her that she was suffering from progressive lung disease of unknown cause. And, yes, in answer to her blunt questions, she would die.

Finally, tired of the poking and endless testing by the Copenhagen doctors, Grethe Rask retreated to her cottage near Thisted. A local doctor fitted out her bedroom with oxygen bottles. Grethe's longtime female companion, who was
a nurse in a nearby hospital, tended her. Grethe lay in the lonely whitewashed farmhouse and remembered her years in Africa while the North Sea winds piled the first winter snows across Jutland.

In Copenhagen, Ib Bygbjerg, now at the State University Hospital, fretted continually about his friend. Certainly, there must be an answer to the mysteries of her medical charts. Maybe if they ran more tests. . . . It could be some common tropical culprit they had overlooked, he argued. She would be cured, and they would all chuckle over how easily the problem had been solved when they sipped wine and ate goose on the Feast of the Hearts. Bygbjerg pleaded with the doctors, and the doctors pleaded with Grethe Rask, and reluctantly the wan surgeon returned to the old Rigshospitalet in Copenhagen for one last chance.

Bygbjerg would never forgive himself for taking her away from the cottage north of the fjord. The virulent microbes that were haunting her body would not reveal themselves in the bombardment of tests she endured in those last days. On December 12, 1977, just twelve days before the Feast of the Hearts, Margrethe P. Rask died. She was forty-seven years old.

Later, Bygbjerg decided he would devote his life to studying tropical medicine. Before he died, he wanted to know what microscopic marauder had come from the African jungles to so ruthlessly rob the life of his best friend, a woman who had been so intensely devoted to helping others.

An autopsy revealed that Grethe Rask's lungs were filled with millions of organisms known as *Pneumocystis carinii*; they had caused a rare pneumonia that had slowly suffocated the woman. The diagnosis raised more questions than answers: Nobody died of *Pneumocystis*. Intrigued, Bygbjerg wanted to start doing research on the disease, but he was dissuaded by wizened professors, who steered him toward work in malaria. Don't study *Pneumocystis*, they told him; it was so rare that there would be no future in it.