Chapter 2
“How Many Dead Hemophiliacs Do You Need?” And the Band Played on (1993)

The early and shameful history of HIV/AIDS\(^1\) in the United States, and the decimation of the U.S. gay population throughout the 1980s and early 1990s, is not well known to the majority of healthcare practitioners who were licensed in the twenty-first century. But it must be, and this film is the conduit. And the Band Played On is a faithful representation of the 1987 630-page book of the same name, written by journalist Randy Shilts. As an openly gay reporter for the San Francisco Chronicle, in a city that had the largest population of gay males at that time—roughly 17% of the city’s population was gay (KQED 2009), Shilts tracked the deadly pandemic from its first appearance around 1979 through the disease’s infancy and early childhood, signing off in 1987, when he completed the book. In “AIDS Years” 1987 was a time-frame that was considered a turning point in HIV/AIDS, when it finally began to be treated like a twentieth century infectious disease instead of a seventeenth century plague, and the year that azidothymidine (AZT), the first anti-retroviral medication for AIDS, was introduced. Shilts refrained from taking the HIV antibody test until he completed the book (CBS 1994); he tested positive and died of AIDS in 1994 at age 42, two years before protease inhibitors were discovered. His greatest contribution to society and medicine was writing down what occurred so that the tragic ethical violations and medical harms that characterized this time period can be taught to future generations of practitioners who now regard AIDS as casually as type 2 diabetes, and who may even see a cure for AIDS in their professional lifetime. While some may never see a patient die from full-blown AIDS or an opportunistic infection, they may be on the front lines of the next pandemic, such as Ebola or COVID-19 (see Chap. 6 and Afterword). Shilts’ work on this critical early period of AIDS is comparable to Daniel Dafoe’s A Journal of the Plague Year (1772), which was about the account of a 1665 outbreak of the bubonic plague in London, as witnessed by one man. Like Dafoe, Shilts tracks AIDS chronologically, across multiple “ground zero” settings, and bears witness to a time and place that is unique in the social and medical history.

\(^1\)See under the History of Medicine section for the history of nomenclature for both the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS).
of the twentieth century. This is a story about intentional medical harms; denial; greed; and the political climate of misusing AIDS to weaponize homophobia and health disparities. For many living Americans who were homophobic in the 1980s, gay males were considered as dispensable a patient population as African Americans in Macon County, Alabama in the 1930s, when the Tuskegee study was underway (see Chap. 1). When the first AIDS cases appeared to be isolated to homosexuals, the prevailing attitude was that it was not a public health problem, but endemic in the gay population due to high-risk sexual behaviors or lifestyles, which mirrored similar misconceptions about syphilis in the African American population in the 1930s. In the early 1980s, most heterosexuals were not interested in the plight of gay males unless they were personally connected to one.

When the first cases of AIDS were reported among hemophiliacs in 1982 it served as evidence that the public blood supply was contaminated by the AIDS virus through blood donors who were infected. Yet the blood industry refused to implement any screening of the public blood supply prior to 1985, when it was much too late. “How many dead hemophiliacs do you need?” is the iconic question that characterizes how AIDS became a public health catastrophe. The question is shouted in the film by Don Francis, a Centers for Disease Control (CDC) physician (portrayed in the film by Matthew Modine), out of frustration and recognition of ethical violations by the blood industry’s failure to act on clear evidence that Factor VIII (clotting factor made from donor blood) was contaminated with the AIDS virus. But because the AIDS virus at this early point was mainly killing gay males and drug addicts—patients few actually cared about at the time—the “handful of hemophiliacs” who contracted AIDS through the public blood supply were considered inconsequential compared to the high cost and inconvenience of screening the blood supply. (This is particularly ironic, considering that Ronald Reagan’s own campaign manager for his 1984 re-election—Roger Ailes—was a hemophiliac.) Moreover, despite growing numbers of transfusion-AIDS cases—particularly in the neonatal, pediatric and post-partum populations—donor screening did not occur until 1985.

Ultimately, And the Band Played On is a “maleficence blockbuster” that harshly, but accurately, judges competent and well-trained health policymakers and some researchers who had the tools and knowledge to contain the AIDS virus, but didn’t because it was too personally and professionally inconvenient.

This chapter discusses the origins of the book and film’s production within the sociological context of the gay liberation movement of the late 1970s in the United States, which abruptly ended in 1981; social misconceptions about AIDS; early AIDS activism and activists such as Larry Kramer; and key historical figures in the social and political history of AIDS, ranging from Rock Hudson to Ryan White. Next, this chapter discusses this film within a History of Medicine context from 1981 to 1993, highlighting early AIDS epidemiology and the facts about Gaetan Dugas (controversially known as “patient zero” in an early cluster study, discussed further); pioneering AIDS researchers, clinician-activists such as Mathilde Krim (co-founder of AMFAR) and Linda Laubenstein (the female doctor in the play “The Normal Heart”); funding issues and failure to screen the blood supply; the discovery of HIV and AZT, as well as how to frame the film in a post-“AIDS cocktail” period (1996 and beyond). Finally, this chapter will discuss the healthcare ethics issues raised in
this film: clear violations of the Principle of Non-Maleficence; health disparities; discrimination and fear, which led to the abandonment of patients; and conflicts of interest that led to delays in prevention and treatment.

**The Life and Times of Randy Shilts: From the Book to the Film**

Randy Shilts, author of *And the Band Played On*, was born in 1951; he was a classic baby boomer who came of age at the height of the Civil Rights movement. Three years before he was born, Alfred Kinsey had published his groundbreaking book, *Sexual Behavior in the Human Male* (1948), which first introduced the Kinsey Scale, and identified homosexuality as part of the “normal” spectrum of male sexual behavior. Kinsey’s work, though controversial at the time, planted the seeds for the next generation of gay males to live openly and begin to “come out”. Shilts was just 18 years old when the Stonewall Riots took place on June 28, 1969—a few weeks shy of Apollo 11. The Stonewall Riots marked the first major “gay civil rights” protest. When the police raided The Stonewall Inn, a gay club in Greenwich Village, its patrons fought back and rioted against the police. The incident marked the beginning of the Gay Liberation Movement, which flourished and peaked in the 1970s, and which also established large gay communities in particular cities, such as San Francisco and New York. In fact, the first HIV infection identified in American gay males was traced to a sexual transmission during a bi-centennial celebration in New York City harbor in 1976 (Shilts 1987).

The philosophy of the Gay Liberation Movement was to celebrate sexual freedom by making sexual activity a focal point in the community, and encouraging gay males (open or closeted) to embrace sexual promiscuity as a banner. One historian recalls (Larsen 2015):

> In 1981, the New York gay community was still living in the heady days of post-Stonewall gay liberation. Gays and lesbians were still fighting for basic legal rights, such as freedom from police harassment, and the current successes of the gay marriage lawsuits were barely a fantasy for most of them. The Gay Pride movement offered gays an ideology of basic self-worth as an antidote to a society that largely ostracized them and viewed them as either mentally ill or morally degenerate and therefore a threat to society. Many in the gay community embraced a hyper-sexualized culture based on free love, partying, and drug use, thereby unwittingly creating ideal conditions for a disease that had been lurking unnoticed in the American population since at least the 1960s because it lacked the opportunity to spread easily.

By the 1990s, the sexualized lifestyle would be labeled “high risk behaviors”. Shilts notes, for example (Shilts 1987: 19):

> This commercialization of gay sex was all part of the scene, an aspect of the homosexual lifestyle in which the epidemics of venereal disease, hepatitis, and entric disorders thrived. The gay liberation movement of the 1970s had spawned a business of bathhouses and sex clubs. The hundreds of such institutions were a $100 million industry across American and Canada, and bathhouse owners were frequently gay political leaders as well, helping support the usually financially starved gay groups.
Dr. Lawrence D. Mass, a New York City physician stated this in 1982 about the spread of AIDS: “gay people whose life style consists of anonymous sexual encounters are going to have to do some serious rethinking.” (Altman 1982)

Upon the book’s release in 1987, the New York Times noted this about the gay community’s promiscuity (Geiger 1987):

With few exceptions, they denied that the epidemic existed except as a homophobic fantasy, fiercely labeled attempts to modify behavior as “sexual facism” and an infringement on civil liberties and failed to mobilize effectively for more funding for research and treatment.

Shilts lived as an openly gay male by age 20 (Weiss 2004). Born in Iowa, and raised in Illinois, he came out while still in college, while he was earning his journalism degree. He worked from 1975 to 1977 for the gay press. Although he struggled to find work as a mainstream journalist due to his lifestyle, he eventually began to cover gay issues for the mainstream press in cities that had large gay communities, including common health problems such as Hepatitis B, which was sexually transmitted.

The title of the book is a nod to the 1912 Titanic disaster, in which the “band played on” as the ship was sinking the night of April 14 and early morning of April 15 until about 1:55 AM, when the last lifeboat was lowered. Until Shilts, the phrase was always connected to the Titanic disaster, based on eyewitness accounts. Musician Wallace Hartley led a string quartet that played on the upper deck all throughout the sinking to calm passengers. The last songs heard were “Nearer My God to Thee” and “Autumn.” Hartley’s last words were apparently: “Gentlemen, I bid you farewell” (Kopstein 2013).

From 1977 to 1980, Shilts worked for an Oakland television news station, covering gay issues, which led to his chronicling of the 1978 assassination of the first openly gay politician in San Francisco, Harvey Milk, who championed the first piece of U.S. legislation to ban gay discrimination. Shilts’ reporting led to his first book, a biography of Harvey Milk, entitled The Mayor of Castro Street: The Life and Times of Harvey Milk (Shilts 1982). In 1984, a documentary entitled The Times of Harvey Milk aired, and in 2008, the film Milk, based on Shilts’ book, was released with Sean Penn (see Chap. 7) in the title role. Shilts began to gain recognition as a superb journalist and next landed a plum job at the San Francisco Chronicle with the assignment of covering the “gay beat”; by 1982, the main story in the gay community was a new “plague” that seemed to be targeting gay males, which was initially labelled GRID—Gay-Related Immune Deficiency—in a May 11, 1982 New York Times article (Altman 1982). Although the article also noted that some were calling the disease “A.I.D.” for Acquired Immune Deficiency, the disease would not be known as AIDS until September 1982 (see under History of Medicine). Thus, Shilts officially became the San Francisco “chronicler” of the early days of AIDS, which turned into a 630-page book, And the Band Played On: Politics, People, and the AIDS Epidemic (1987). Shilts stated: “Any good reporter could have done this story, but I think the reason I did it, and no one else did, is because I am gay. It was happening to people I cared about and loved” (Grimes 1994). The book was explosive in its condemnation of policy makers and decision-makers. Shilts states in his prologue (Shilts 1987):
The book (and later, film) tracks five main political theaters of early AIDS history: (1) the gay community: patients, partners, caregivers, the gay “libertarians” and sexual freedom fighters, as well as their opponents—gay advocates for risk reduction and safe sex; (2) the clinicians on the ground dealing with lack of resources for AIDS patients; (3) the public health professionals [from local to the CDC] embroiled in risk reduction strategies and “screening battles” to protect the public blood supply; (4) the Reagan Administration response; and (5) the battle over credit for the discovery of the AIDS virus, which has become known as one of the most infamous research ethics stories. The book tells these stories simultaneously in chronological, not thematic order. At the time, the book created a fast-paced, dizzying adventure story with multiple subplots and characters. The film version is faithful to this style of narrative, and mirrors the same pace with the same effects.

In a November 1987 *New York Times* review (Geiger 1987), it was clear the book was being published in the center of an uncontrolled epidemic:

> We are now in the seventh year of the AIDS pandemic, the worldwide epidemic nightmarishly linking sex and death and drugs and blood. There is, I believe, much more and much worse to come...And so acquired immune deficiency syndrome is not only an epidemic; it is a mirror, revealing us to ourselves. How did we respond? [The book] is at once a history and a passionate indictment that is the book’s central and often repeated thesis.... A majority of the anticipated tens of thousands of 1991 New York City AIDS patients will be black and Hispanic intravenous drug users, their sexual partners and their babies.

However, to a 1987 reader, the multiple political theaters unfolding in the book were difficult to grasp; the book review also noted the following (Geiger 1987):

> There is also the clinical story of physicians struggling both to treat and care for AIDS patients - desperately comparing notes, searching the medical journals, fighting for hospital beds and resources. There is the story of the scientific research that led at last to a basic understanding of the disease, the identification of the virus, the test for antibodies. And, finally, there is the larger political and cultural story, the response of the society, and its profound impact on all the other aspects of the AIDS epidemic.

> Mr. Shilts tells them all - but he tells them all at once, in five simultaneous but disjointed chronologies, making them all less coherent. In the account of a given month or year, we may just be grasping the nature of the research problem - and then be forced to pause to read of the clinical deterioration of a patient met 20 or 40 or 60 pages earlier, and then digress to a Congressional hearing, and then listen to the anxious speculations of a public health official and finally review the headlines of that month. The threads are impossible to follow.

> The reader drowns in detail. The book jacket says that Mr. Shilts - in addition to his years of daily coverage of the epidemic - conducted more than 900 interviews in 12 nations and
dug out thousands of pages of Government documents. He seems to have used every one of them. Reading And the Band Played On sometimes feels like studying a gigantic mosaic, one square at a time.

Indeed, it does. That is why the 1993 film version, faithful to the book’s pace and narrative, suffices for new generations of learners who may not have the three months that it takes to read the entire book. However, Shilts’ 630 pages age very well, and have become the “go to” for any medical historian wishing to document this period of history. With only a few exceptions noted further on, Shilts’ historical account holds, and also led to a scathing analysis of organizational decision-making by the Institute of Medicine in 1995 (see under History of Medicine).

**An AIDS Book in the Reagan Era**

When Shilts’ book is published in 1987, Ronald Reagan, one of the most popular Republican Presidents to date, was finishing his second term, had survived an assassination attempt in his first term (March 30, 1981 by John Hinckley Jr., who was found not guilty by reasons of insanity), and would be successful in being elected for a “third term” of sorts, when voters chose his Vice President, George H. W. Bush (aka “Bush 41”) in 1988 to continue his agenda, including the “slow walk” on AIDS policy. As mentioned earlier, considering that both Reagan and Bush 41 were very dependent on infamous Republican strategist Roger Ailes—a hemophiliac—for getting elected, the disconnect of ignoring AIDS is notable, since Ailes no doubt was probably taking clotting factor VIII before the blood supply was screened. Reagan was not a supporter of gay rights, and made that clear in his 1980 bid for the presidency: “My criticism is that [the gay movement] isn’t just asking for civil rights; it’s asking for recognition and acceptance of an alternative lifestyle which I do not believe society can condone, nor can I” (Scheer 2006).

Prior to 1985, AIDS was not a major topic of concern for most Americans. As hundreds of gay males in San Francisco began to drop dead between 1981 and 1984, another part of the Bay Area was flourishing as the PC Revolution took shape; Microsoft and Apple started, and the famous “Macintosh 1984” commercial aired December 31, 1983. Most Americans have memories during this period not of AIDS, but of Madonna, Michael Jackson’s “Thriller” album, and Bruce Springsteen’s “Born in the USA” album as the soundtrack to a time frame of shameless promotion of materialism, opulence and greed, demonstrated in the film, *Wall Street* (1986). The biggest fears amongst most heterosexual American liberals between 1981 and 1984 centered on nuclear holocaust as Reagan poured billions into increased defense, and ramped up tensions with the Soviet Union. An entire genre of 1980s nuclear war films abounded around Reagan’s first term: *The Day After* (1983); *Testament* (1983); *War Games* (1983); the horrific British film, *Threads* (1984); and the animated film, *When the Wind Blows* (1986). Reagan actually changed his nuclear policies as a result of watching *The Day After*. 
In October 1985, when actor Rock Hudson died of AIDS (see further), a flurry of heightened mainstream media coverage of the AIDS epidemic followed. Shilts, in fact, divides early AIDS history into “before Rock” and “after Rock” (see further). Reagan famously avoided all discussion of AIDS during the entire first term of his presidency; he mentioned it for the first time in 1985 in the aftermath of Hudson’s death, after approximately 4000 Americans had died from AIDS (a greater number than those killed on 9/11 and roughly the same number of American troops killed in the Iraq war), and roughly 8000 had been infected (Avert 2018) by then. Reagan began to mention AIDS in several speeches in 1987, which was likely due to the popularity of Shilts’ book.

By 1987, AIDS was beginning to penetrate into heterosexual lives more significantly. The third top-grossing film of that year was Fatal Attraction, which was not about AIDS per se, but about how sex with the wrong person can literally kill your whole family. Fatal Attraction resonated with heterosexuals on a range of levels, but ultimately was a film that demonstrated the depths to which having unprotected sex can harm you. At the same time, another high-grossing film, Three Men and a Baby, which featured three heterosexual men living together and raising a baby as a result of a one-night stand of one of them—also resonated culturally, as “macho” heterosexual men were portrayed here as maternal, capable of caregiving, and taking ownership of consequences of their sexual partners. Young adults coming of age in this period—demonstrated in sitcoms such as Family Ties, for example—had the opposite experiences of their parents, who grew up during the Sexual Revolution. Yet another 1987 film, inspired by misplaced “nostalgia” for easier sexual times, was Dirty Dancing (see Chap. 5). This film was yet another cautionary tale about unprotected sex, in which the entire plot revolves around an unwanted pregnancy and unsafe abortion. Viewers of Dirty Dancing are also aware of a growing epidemic of maternal transmission of AIDS, and transfusion AIDS in the neonatal setting. In essence, three major films in 1987 that are not specifically about AIDS, are still about the consequences of unprotected sex, reflecting the cultural anxieties over AIDS. If you were in college at this time, HIV testing and condoms became part of the college scene. By December 1, 1988, the first Annual AIDS Day was launched, marking the end of the Reagan era, and the start of the Bush 41 era, which was also noted for an “appalling” record on AIDS, discussed further (Thrasher 2018).

Ultimately, Reagan’s first term coincided with the “Moral Majority” movement, in which conservative Christians dominated the political agenda, openly voicing fear and loathing of homosexuals and anyone else with AIDS. However, by the end of Reagan’s second term, the Moral Majority had begun to dissolve as a movement (later re-emerging as the religious right base of the Republican Party), while AIDS was no longer considered a “gay disease” but a political one, largely due to Shilts’ book. Shilts recalled in an interview in 1987 (Geiger 1987):

If I were going to write a news story about my experiences covering AIDS for the past five years, the lead would be: In November of 1983, when I was at the San Francisco Press Club getting my first award for AIDS coverage, Bill Kurtis, who was then an anchor for the ‘CBS Morning News,’ delivered the keynote speech…He started with a little joke…In Nebraska the day before, he said he was going to San Francisco. Everybody started making AIDS
jokes and he said, ‘Well, what’s the hardest part about having AIDS?’ The punch line was, ‘Trying to convince your wife that you’re Haitian.’ …[THIS] says everything about how the media had dealt with AIDS. Bill Kurtis felt that he could go in front of a journalists’ group in San Francisco and make AIDS jokes. First of all, he could assume that nobody there would be gay and, if they were gay, they wouldn’t talk about it and that nobody would take offense at that. To me, that summed up the whole problem of dealing with AIDS in the media. Obviously, the reason I covered AIDS from the start was that, to me, it was never something that happened to those other people.

Shilts’ book remained on the New York Times best-seller list for five weeks, and was nominated for a National Book Award. Unbeknownst to his readers, Shilts got an HIV test the day he turned in his manuscript to his publisher, and discovered he was HIV-positive in March 1987 (Michaelson 1993). He chose not to disclose he was HIV positive because “Every gay writer who tests positive ends up being an AIDS activist. I wanted to keep on being a reporter” (Grimes 1994). He progressed to AIDS in 1992, and finished his next book on gays in the military, Conduct Unbecoming (1993), from his hospital bed (Schmalz 1993). That book inspired the opening act of the Clinton Administration—the “don’t ask, don’t tell” policy (see further). In February 1993, when Shilts was 41, he publicly disclosed he had AIDS, stating: “I want to talk about it myself rather than have somebody else talk” (Michaelson 1993). Shilts lived to see And the Band Played On made into a film.

**The Life and Times of Larry Kramer**

Shilts’ book also covered extensively the “life and times” of writer, playwright and activist, Larry Kramer (1935–2020), which the film, does not document, due to too much complexity. For these reasons, I would suggest that when screening And the Band Played On as part of a comprehensive course on the history of AIDS, one should also assign as companion works, the HBO feature film, The Normal Heart (2014) and/or the HBO documentary, Larry Kramer: In Love and Anger (2015), which thoroughly covers Kramer’s rightful place in early AIDS history. I provide a more concise recap here.

Kramer’s early activism career started with a controversial novel, Faggots (1978), which was autobiographical in nature, and critically questioned the Gay Liberation movement, and the unhealthy lifestyle sexual promiscuity encouraged, including the activities that went on in gay bathhouses (see earlier). The book warns that such a lifestyle may be dangerous, and suggests that monogamy, and not promiscuity, should be what gay males strive for. The book was attacked by the gay press for daring to “preach” about sexual liberation. When the first cases of AIDS began to proliferate in New York City, Kramer was an early believer that it was likely sexually transmitted, and advocated for risk reduction through reducing sexual activity. In 1981, eighty men gathered in Kramer’s apartment to discuss raising awareness and money for “gay cancer”—before the term GRID was used; that meeting led to the formation of the Gay Men’s Health Crisis (GMHC) in 1982, with founding co-members, Nathan
Fain, Larry Mass, Paul Popham, Paul Rapoport, and Edmund White. The organization functioned as a social and healthcare services organization: “An answering machine in the home of GMHC volunteer Rodger McFarlane (who will become GMHC’s first paid director) acts as the world’s first AIDS hotline—it receives over 100 calls the first night” (GMHC.org). That same year, GMHC produced the first informative newsletter about the AIDS crisis that went to roughly 50,000 readers comprising doctors, hospitals, clinics and the Library of Congress. GMHC also introduced the “Buddy program” which is modeled in countless organizations today; volunteers would visit and care for the sick in their community, and often would go to their hospital rooms to care for them when nurses refused to touch them.

In March 1983, Kramer authored an essay in a gay magazine titled: “1,112 and Counting” (Kramer 1983), which I discuss further on (see under Healthcare Ethics issues). The essay remains a masterpiece of advocacy journalism but can be categorized as one of the first clinical ethics articles documenting discrimination and moral distress in the AIDS crisis. Shilts notes this about “1112 and Counting” (Shilts 1987: 244):

> With those words, Larry Kramer threw a hand grenade into the foxhole of denial whre most gay men in the United States had been sitting out the epidemic. The cover story of the New York Native, headlined “1,112 and Counting” was Kramer's end run around all the gay leaders and GMHC organizaers worried about not panicking the homosexuals and not inciting homophobia. As far as Kramer was concerned, gay men needed a little panic and a lot of anger.

AIDS was handled differently in New York City, where Ed Koch is mayor, than in San Francisco, where progressive Dianne Feinstein is mayor at the time. Koch was a closeted gay male (Shilts 1987; Kramer 1983), who refused to address AIDS in his community. Koch represented a genre of closeted American gay politicians—still seen today—who display a public “anti-gay” ultra-Conservative face, in contrast to their private lives. Ultimately, Kramer's aggressive style of activism was so politically incorrect and unpopular, it led to his being ousted by his own GMHC Board of Directors. Kramer next wrote the powerful play, “The Normal Heart”, which debuted off Broadway in 1985—while Shilts is still chronicling the early years of the epidemic. “The Normal Heart” told the incredible story—in real time—of men dying of AIDS in New York City completely alone and abandoned, and the frustrations of the health-care workers and eyewitnesses at “ground zero”, as well as Kramer's experiences with GMHC. Shilts’ recounts the opening night of the play like this (Shilts 1987: 556):

> A thunderous ovation echoed through the theater…True, The Normal Heart was not your respectable Neil Simon fare, but a virtually unanimous chorus of reviewers had already proclaimed the play to be a masterpiece of political drama…One critic said Heart was to the AIDS epidemic what Arthur Miller’s The Crucible had been to the McCarthy era. New York Magazine critic John Simon, who had recently been overheard saying that he looked forward to when AIDS had killed all the homosexuals in New York theater, conceded in an interview that he left the play weeping.

The reviews were critical. From the New York Times, with Bruce Davison cast as the “Kramer” character, Ned Weeks (Rich 1985):
The blood that’s coursing through “The Normal Heart,” the new play by Larry Kramer at the Public Theater, is boiling hot. In this fiercely polemical drama about the private and public fallout of the AIDS epidemic, the playwright starts off angry, soon gets furious and then skyrockETS into sheer rage. Although Mr. Kramer’s theatrical talents are not always as highly developed as his conscience, there can be little doubt that “The Normal Heart” is the most outspoken play around - or that it speaks up about a subject that justifies its author’s unflagging, at times even hysterical, sense of urgency…. The trouble is not that the arguments are uninteresting, but that Mr. Kramer is not always diligent about portraying Ned’s opponents…The more the author delves into the minutiae of the organization’s internecine politics, the more “The Normal Heart” moves away from the larger imperatives of the AIDS crisis and becomes a parochial legal brief designed to defend its protagonist against his political critics.

From the Los Angeles Times, with Richard Dreyfus in the role: (Sullivan 1985).

Beneath the social concerns of “The Normal Heart” is the story of a man who must learn to adjust his expectations of other men downward if he hopes to do any good among them. This is interesting. So is the play’s message that having sex with as many partners as desired is actually a kind of addiction. What play in the liberated ’70s and ’80s has dared to say that?” As an AIDS documentary, it is also already something of a period piece, thank God: The causes of the disease have been more clearly pinpointed now.

The play’s revival on Broadway in 2011, featured an open letter in the playbill to the audience that read, in part (Gans 2011; Nuwer 2011):

Thank you for coming to see our play.

Please know that everything in The Normal Heart happened. These were and are real people who lived and spoke and died, and are presented here as best I could. Several more have died since, including Bruce, whose name was Paul Popham, and Tommy, whose name was Rodger McFarlane and who became my best friend, and Emma, whose name was Dr. Linda LaubenStein. She died after a return bout of polio and another trip to an iron lung. Rodger, after building three gay/AIDS agencies from the ground up, committed suicide in despair. On his deathbed at Memorial, Paul called me (we’d not spoken since our last fight in this play) and told me to never stop fighting.

Four members of the original cast died as well, including my dear sweet friend Brad Davis, the original Ned….

Please know that AIDS is a worldwide plague…Please know that no country in the world, including this one, especially this one, has ever called it a plague, or acknowledged it as a plague, or dealt with it as a plague.

Despite the reviews, which seem to prefer another AIDS play—“As Is”, which opened a month before Kramer’s—“The Normal Heart” play was a big hit, and Kramer next founded AIDS Coaltion to Unleash Power (ACT UP), which staged a number of groundbreaking activist-led “performance art” that literally sped up AIDS drug development, treatment, and AIDS patients’ access to experimental protocols and clinical trials (see under History of Medicine). ACT UP formed in March 1987, the same year And the Band Played On was published. Both Shilts and Kramer played integral, if not, symbiotic roles in helping to make AIDS a political priority. ACT UP
was particularly active during the Bush 41 era, staging all kinds of creative protests in front of the White House and around D.C. Kramer was one of the few AIDS survivors of his generation, who lived long enough to take advantage of AZT and then protease inhibitors (see under History of Medicine).

**Paper Covers Rock: From Rock Hudson to amfAR**

The story of the early days of AIDS is incomplete without discussing actor Rock Hudson (whose real name was Roy Harold Scherer, Jr. until it was changed by his agent), the first celebrity to admit that he was dying from AIDS, blowing his carefully concealed cover that he was gay. Shilts writes about the “before Rock” and “after Rock” timeframes, as after Hudson came forward, media coverage about AIDS abounded, and the American Foundation for AIDS Research (amFAR) was founded.

Rock Hudson (1925–85) was a closeted 6-foot 4-inch gay actor who was the picture of heterosexual machismo, and “tall, dark and handsome” leading man. He made a number of romantic comedies with actress Doris Day; they were reunited on July 16, 1985 to promote a cable show Day was doing for the Christian Broadcasting Network on pets. Hudson’s appearance and demeanor were so alarming, it led to rumors about his health; many in Hollywood who knew he was gay actually suspected cancer (Collins 1992). The footage of Hudson and Day was repetitively aired, and is one of the few presentations of Hudson with late stage AIDS. Hudson was a patient of Dr. Michael Gottlieb at UCLA, who authored the first paper on AIDS in 1981 (see under History of Medicine). Hudson was one of the first AIDS patients to be treated with experimental HPA-23 antiretroviral drug therapy at the Pasteur Institute in Paris (see under History of Medicine); he was diagnosed in 1984 while he was starring in the television series, *Dynasty*. When Hudson collapsed in his Paris hotel lobby on July 25, 1985 and was flown back to UCLA, his publicist admitted he was in Paris receiving treatment for AIDS. This was groundbreaking, and big news. When AIDS began to kill off many celebrities in the early 1980s, most of the AIDS-related Hollywood obituaries would not openly state the cause of death other than “long illness” and sometimes “pneumonia” (Shilts 1987). Hudson was the first to make the morally courageous and consequential decision to announce he was undergoing treatment for AIDS. Hudson’s close friend, Elizabeth Taylor, came to visit him when he was in the hospital that August, and met his doctor, Gottlieb. She approached Gottlieb after her first visit to help get her to the hospital in a less publicized fashion, and he picked her up and took her to the hospital, using a side-entrance typically reserved for faculty and staff. Taylor and Gottlieb formed a friendship.
**AIDS Project L.A. and the Commitment to Life Dinner**

While Hudson was ill, a former gay Xerox executive, Bill Misenhimer, had formed an AIDS patient services organization called AIDS Project Los Angeles (APLA), which was planning a big fundraising dinner for September 19, 1985. Misenhimer contacted Taylor to chair and host the gala dinner which they were calling the “Commitment to Life” dinner. Taylor’s interest in helping was also motivated by the fact that her own daughter-in-law (Aileen Getty) had been diagnosed with AIDS that same year (1985), and was presumed to be infected through IV drug use (Dulin 2015). As Gottlieb and Taylor got to know one another, they had an impromptu dinner with Misenhimer and Taylor’s publicist (Chen Sam) to discuss the gala event, and then transitioned to discussion of Taylor and Gottlieb forming a national AIDS foundation they would call National AIDS Research Foundation (NARF). Next, Hudson told Gottlieb and Taylor that he would donate $250,000.00 to help NARF get off the ground. On September 19, 1985, the Commitment to Life charity dinner was a huge success, netting $1 million for APLA. Hudson prepared a statement to be read by Burt Lancaster to the 2500 persons in attendance at the dinner (Higgins 2015):

> I am not happy that I am sick; I am not happy that I have AIDS. But if that is helping others, I can, at least, know that my own misfortune has had some positive worth.

At the same dinner, Burt Reynolds read a telegram from Ronald Reagan, which the *Los Angeles Times* reported the next morning as follows (Oates 1985):

> A page-long statement from Reagan, read by Reynolds, said “remarkable progress” had been made in efforts to conquer the disease, but “there is still much to be done.”

> Scattered hissing broke out in the audience when Reynolds read a line that began: “The U.S. Public Health Service has made remarkable progress …”

> Reynolds stopped reading and told the audience that “I don’t care what your political persuasion is, if you don’t want the telegram read, then go outside.”

> There was applause and Reynolds continued to read the statement.

Reagan, who spoke out publicly on acquired immune deficiency syndrome for the first time at a news conference earlier this week, said the fight against the disease is a “top priority” of his Administration but told supporters of the AIDS Project that “we recognize the need for concerted action by organizations like yours, devoted to education, support services and research.”

**Birth of amfAR**

When AIDS researcher, Mathilde Krim (see amfar.org) heard about Hudson’s donation, she contacted Gottlieb to discuss joining forces (Collins 1992). Krim was a basic AIDS researcher at Memorial Sloan Kettering in New York City. In 1983, Krim and several of her colleagues had formed the AIDS Medical Foundation. Gottlieb got Krim and Taylor together, and they decided to pool their efforts and resources
and merge into one organization they renamed the American Foundation for AIDS Research (amfAR), with Taylor as the famous face of the organization as its National Chair and spokesperson. Ultimately, Hudson’s initial donation, combined with individual donations after his death for AIDS research, is what led to independent funding of AIDS research beyond the limitations and constraints of federal agencies. On September 26, 1985, Taylor, Gottlieb and Krim announced the formation of amfAR at a press conference.

Hudson’s Death

Rock Hudson died on October 2, 1985, and AIDS was announced as the cause of death. Hudson’s death helped destigmatize AIDS into a disease worthy of charitable donations—something that was not possible before. Through amfAR, Taylor used her fame to secure millions of dollars in fundraising for AIDS research; she also coached Ronald Reagan to speak at one of amfAR’s first major fundraisers in 1987, in which Reagan made controversial comments about the need for “mandatory testing”, which was contrary to expert recommendations (see under History of Medicine). By 1992, Taylor’s efforts led to amfAR raising $20.6 million in funding (Collins 1992), which was a staggering amount for one organization; she was featured on the cover of Vanity Fair with the title “Liz Aid” which stated:

No celebrity of Taylor’s stature up to that point had had the courage to put his or her weight behind a disease that was then thought to be the province of gay men. Elizabeth Taylor brought AIDS out of the closet and into the ballroom, where there was money—and consciousness—to be raised.

In teaching about the early history of AIDS, it’s important to discuss Hudson’s and Taylor’s roles as countless extramural grants were funded because of them. Without Hudson and Taylor, AIDS funding at the levels needed at that time would not have occurred, nor would thousands of basic AIDS research careers.

An easy way to showcase Hudson and Taylor together is by presenting some clips from the film Giant (1956).

From Band to Bush: AIDS in the Bush 41 Era

In 1988, Reagan’s Vice President, George H. W. Bush, was the Republican nominee for President, facing off against Massachusetts Governor Michael Dukakis, who was leading by 15 points. Bush approached one of the most heralded Republican strategists, Roger Ailes (later CEO of Fox News), who had also worked on Reagan’s 1984 campaign, and Nixon’s 1968 campaign. Ailes was also in a high-risk group for being infected with HIV because he had hemophilia. Ailes worked with Bush’s campaign manager, Lee Atwater, playing the “race card” with the infamous Willy
Horton ad, which was a negative ad about Governor Dukakis’ prison reform policies, featuring an African American inmate, Willy Horton, who committed crimes while on a weekend furlough (Bloom 2018). The ad played to white voters’ fears of African Americans raping them. It was the ad that led to Bush being elected, and a continuation of tepid AIDS policies, coinciding in 1990 with the death of Ryan White (see further). In 1992, Elizabeth Taylor was asked about Bush’s AIDS policies at the Eighth International Conference on AIDS in Amsterdam. She stated: “I don’t think President Bush is doing anything at all about AIDS. In fact, I’m not even sure if he knows how to spell ‘AIDS.’ ”

On September 18, 1989, the National Commission on AIDS (created November 4, 1988—a week before Vice President George H. W. Bush would be elected as the 41st President) met for the first time.

The Bush 41 era was also the timeframe in which Shilts’ book was being optioned and considered for a film. The 10th year of AIDS was marked during the Bush 41 era, in June 1991, a decade after the first article appeared on Kaposi’s sarcoma (see under History of Medicine). But a decade into the deadly epidemic with no cure began to take its toll on the American psyche and healthcare infrastructure, and was no longer a “gay disease”. During the Bush 41 era, three prominent heterosexual cases of HIV infection would begin to shift public opinion about AIDS, and public opinion about Bush, who seemed stuck in the early 1980s.

**The Ryan White Story**

Ryan White (1971–1990) was a child in Indiana with hemophilia who was diagnosed with AIDS in 1984; he had been infected through a blood supply product, Factor VIII. His story was widely publicized during Reagan’s second term, which revolved around his battle with the school boards to be allowed to attend his public school. During the Reagan era, he became the face of the social story of pediatric AIDS, as he endured intense discrimination. But Ryan’s “superstardom” as an AIDS activist hit its stride during the Bush 41 years due to the ABC television film that aired in 1989: *The Ryan White Story*, which made him into a moral hero for pediatric AIDS patients, as he used his cause celeb to champion AIDS public education in countless public forums. White attracted a lot of famous friends, including Elton John and Michael Jackson, who gave him a car in 1988. Just prior to Bush’s inauguration, a *New York Times* review on the White film was published, which stated the following (O’Connor 1989), hinting at barriers faced by producers working with Shilts’ material for film:

> The vast majority of AIDS patients are homosexuals and drug addicts, but television apparently is not ready to explore these groups with any degree of compassion. Innocent youngsters trapped by circumstances beyond their control provide far easier dramatic hooks for uplift exercises.

Still, these stories are indeed heartbreaking and do serve as vehicles for exposing public ignorance and prejudice about AIDS. “The Ryan White Story” at 9 o’clock tonight on ABC is a good case in point. It is the true story of a remarkably gutsy 13-year-old whose battle to continue going to school made national headlines. A hemophiliac, Ryan discovered he had
AIDS a little over four years ago. At the time, he was given three to six months to live. He is still active today, occasionally visiting schools around the nation to tell his story.

It is a story not only about ignorance but also about an almost total lack of enlightened community leadership in the city of Kokomo. Residents are understandably concerned and frightened, but panic is allowed to take over. Petitions to keep Ryan out of school are signed not only by neighbors but also by the local police. A radio station broadcasts vicious bilge. The print and electronic press push for sensationalism. The Whites find a bullet hole in their living-room window. Ryan is systematically isolated and ostracized…. It is not a pretty story. Worse, it is a story that didn’t have to happen.

Bush 41 was inaugurated just days after ABC’s White film begins to change hearts and minds, but Bush is still stuck in the Reagan era on the policy front. He is blindsided by a shift in public sentiment calling for greater action on AIDS. His administration was faulted for underfunding the growing epidemic as the magnitude of transfusion AIDS cases was unfolding, as well as maternal transmission cases. Transfusion AIDS cases were not just due to a failure to screen the blood supply prior to 1985, but a failure to warn patients needing transfusions of these risks when the blood supply was unsafe (see under Healthcare Ethics Issues), a fact that the film, And the Band Played On, highlights for its 1993 audience. Additionally, White’s story of discrimination resonates within the African American community, which by now is experiencing an explosion of AIDS cases (see further). By this time frame, homophobia and cruel discrimination against AIDS patients persisted; health disparities regarding screening and testing persisted; and the costs of treatment mounted. Bush was unable to contain anger and frustration over a lack of basic infrastructure for AIDS patients, who were often unable to get, or maintain: health insurance, adequate housing, education or employment, or even adequate end of life care or hospice. By the time Ryan White died in 1990, Bush had inherited national rage regarding general underfunding of AIDS healthcare, while there were real limits to the efficacy of AZT. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act passed in 1990 (see under History of Medicine), which was a healthcare “payor of last resort” for HIV/AIDS patients; in retrospect, it was one of the most significant pieces of AIDS legislation passed by Congress, but its benefits did not kick in until 1991, and its reach would not be completely realized until Bush was out of office, as resource allocation issues abounded after passage (see further). The legislation was seen as too little too late: by 1990 over 100,000 Americans had died of AIDS—nearly twice the number of Americans who died in the Vietnam War, while AIDS had become the number one cause of death for U.S. men ages 25–44 (GMHC 2018).

If White was one transfusion AIDS case bookend to the start of Bush’s presidency, Arthur Ashe (see further) was the transfusion AIDS case bookend at the end of his term. But Magic Johnson would bridge the two, and he ultimately humiliated Bush by calling him out on his AIDS policy failures.
Earvin “Magic” Johnson: From NBA to the National Commission on AIDS

On November 7, 1991, the famous basketball player, Magic Johnson, publicly announced that he had tested positive for HIV and was retiring from the L.A. Lakers team and the NBA. Johnson traced his infection to unprotected heterosexual activities when he had been single and promiscuous, and made clear that his wife and daughter were not infected. Johnson was one of the first famous figures infected through heterosexual contact, and always denied being bisexual or gay (Friend 2001).

In response, Bush appointed Johnson to the National AIDS Commission his administration initiated by federal statute, which consisted of 15 members appointed by Congress and the White House. The AIDS Commission had recommended expansion of Medicaid to cover low income people with AIDS and universal healthcare to deal with healthcare access, disparities and the growing number of those infected with HIV as well as AIDS patients. Johnson was acutely aware of disparities in the African American community, echoing the same problems found with the Tuskegee issues (see further).

But none of these recommendations were taken up by the administration. Eight months later, Johnson quit, stating that the Bush Administration had “dropped the ball” on AIDS (Hilts 1992a, b):

As I think you know, along with my fellow commission members I have been increasingly frustrated by the lack of support, and even opposition, of your Administration to our recommendations – recommendations which have an urgent priority and for which there is a broad consensus in the medical and AIDS communities…I cannot in good conscience continue to serve on a commission whose important work is so utterly ignored by your Administration.

Johnson went on to be an HIV/AIDS “super-educator”, which continues today, and also played professionally again by 1996, when the drug cocktail became available (see further). Ultimately Johnson’s role on the Bush AIDS Commission was a micro-cosm of AIDS policy in the Bush 41 era: all talk—an improvement over Reagan’s refusal to even talk about it—but alas, no action that translated into meaningful healthcare delivery for AIDS patients. If the Reagan years were about committing to funding for AIDS research, the Bush years were about getting a commitment to fundamental AIDS healthcare delivery, which did not occur; “last resort” healthcare was not the same thing.

The Arthur Ashe Case

Arthur Ashe (1943–93) was an African American tennis player and intellectual; he was the first African American to win Wimbledon. He had been active in a variety of human rights causes, including protesting apartheid in South Africa (Barker 1985). In the scholarly world, he was known for a three-volume history of black athletes in the United States (Ashe 1993).
In 1979, Ashe suffered a heart attack, even though he was fit and in his 30s. This forced him to retire in 1980. He wrote the following about his heart disease in the *Washington Post* (Ashe 1979):

**Why me?**

The why-me question was more than just a complaint from someone who felt cheated by fate. It was a serious question.

I’m not your typical heart attack victim. My blood pressure is below normal. I don’t smoke or take drugs. I’m thin. My serum cholesterol count is low. I’m not hypertense. I have no trouble absorbing sugar. And with all the tennis I play, I’m about as physically fit as a 36-year-old man can be.

Maybe all of this explains why I didn’t pay much attention at first to the chest pains. The first four incidences of pain lasted two minutes apiece and disappeared – I thought for good.

Ashe had quadruple bypass surgery in 1979. He then needed a double bypass surgery in 1983, which is when he became infected with HIV from a blood transfusion during that surgery. He didn’t realize he was infected until he was hospitalized for bizarre symptoms in 1988, and he was diagnosed with AIDS when he was found to have an opportunistic disease. He wanted to keep his illness private, but when a *USA Today* reporter learned of it from an unnamed hospital source—making the eventual case for the privacy rule of the Health Insurance Portability and Accountability Act (HIPAA)—Ashe was given the opportunity to disclose it himself before they published the story. Ashe contacted the *USA Today*’s sports editor, Gene Polincinski, to request 36 hours for him to pull together a press conference and announce it himself. In other words, Ashe was forced to disclose he had AIDS due to confidentiality violations. Ashe’s case helped to pave the way to the HIPAA privacy rules that were passed in 2003. Ashe disclosed he had AIDS April 8, 1992 (Walton 2017):

Beginning with my admittance to New York Hospital for brain surgery in September 1988, some of you heard that I had tested positive for HIV, the virus that causes AIDS. That is indeed the case…I am angry that I was put in a position of having to lie if I wanted to protect my privacy…I did not want to have to go public now because I’m not sick. I can function very well and I plan to continue being active in those things I’ve been doing all along—if the public will let me.

He also stated (Reimer 1992; Parsons 1992):

There is no good reason for this to have happened now. I didn’t commit any crime. I’m not running for public office. I should have been able to keep this private… Still, I didn’t commit any crimes and I’m not running for public office. I should be able to reserve the right to keep things like that private. After all, the doctor-patient relationships are private…There was certainly no compelling medical or physical necessity to go public with my medical condition.

On April 12, 1992, Ashe penned a scathing editorial in the *Washington Post* (Ashe 1992) entitled “Secondary assault of AIDS spells the public end to a private agenda”, in which he wrote the following:
I’m pissed off that someone would rat on me, but I’m even more angered that I would have had to lie to protect my privacy… I wasn’t then, and am not now, comfortable with being sacrificed for the sake of the “public’s right to know.” …

“Going public” with a disease such as AIDS is akin to telling the world in 1900 that you have leprosy. Fortunately, this general reaction is abating somewhat as people such as Magic Johnson show that one need not shun an AIDS victim…Since I was not sick, I felt no compelling need to tell anyone who didn’t need to know. … Keeping my AIDS status private enabled me to choose my life’s schedule. That freedom now has been significantly eroded. Will I be able, for instance, to fulfill my duties as an HBO broadcaster at Wimbledon? I assume so, but I’m not sure. When I give a tennis clinic for kids somewhere, will they shy away for no good reason except parental caution?

After going public (Freeman 1992), he formed the Arthur Ashe Foundation for the Defeat of AIDS. As an African American, Ashe was continuously misrepresented as having contracted AIDS through sex (like Johnson), but like Johnson, he was also an unintentional spokesperson for health disparities in the African American communities who were becoming the fastest growing population of AIDS patients due to the “legacy of Tuskegee” (see further). Ashe was also arrested while protesting the Bush Administration’s treatment of Haitian refugees fleeing a military coup at the time (Finn 1993). Haitians who were HIV-positive were either refused entry into the United States, or held in quarantine if they were at high risk of being infected with HIV.

The Arthur Ashe story and saga followed Bush through an election year. Although Bush was praised for leading the end of the Cold War, as well as his handling of the Gulf War, he was unable to win approval for his handling of AIDS, or his domestic policy achievements. He seemed unable to demonstrate empathy (by 1992 standards), which did not look good next to Bill Clinton, who oozed empathy and was the Democratic nominee for President in the 1992 election. At a debate with Clinton and Ross Perot, Bush actually said this about AIDS when defending his Administration’s policies:

It’s one of the few diseases where behavior matters. And I once called on somebody, “Well, change your behavior! If the behavior you’re using is prone to cause AIDS, change the behavior!” Next thing I know, one of these ACT UP groups is saying, “Bush ought to change his behavior!” You can’t talk about it rationally!

Clearly, this response indicated that Bush had no real understanding or appreciation of transfusion AIDS cases or pediatric AIDS, which had nothing to do with anyone’s behavior but the blood industry’s decision-makers. Ashe died February 6, 1993, just a few weeks after Bill Clinton was inaugurated.

**The Legacy of Tuskegee: AIDS and African Americans**

The story of the Tuskegee study, exhaustively discussed in Chap. 1, was only comprehensively brought to light in the time of AIDS through James Jones’ groundbreaking
book, *Bad Blood: The Tuskegee Syphilis Experiment*, which was released in June 1981, coinciding with the June 5, 1981 article in *Morbidity and Mortality Weekly Report (MMWR)*, entitled “Pneumocystis pneumonia” (CDC 1981a), the very first published medical article about HIV/AIDS. The CDC followed up with a second article a month later in *MMWR* on the outbreak of Kaposi’s sarcoma in a similar population (CDC 1981b). As Jones’ book is being read, the AIDS crisis is unfolding, and begins to make its way into the African American communities—particularly through intravenous (IV) drug use and needle sharing—by the mid-1980s. By 1988: “For the first time, more new AIDS cases in NYC are attributed to needle sharing than to sexual contact. The majority of new AIDS cases are among African Americans; people of color account for more than two thirds of all new cases” (GMHC 2018). Although there was a catastrophic rise in HIV/AIDS cases, because of what would be called the “legacy of Tuskegee,” distrust of “government doctors” from the CDC, NIH, and other public health agencies, led to resistance by the African American communities to get tested, screened, or practice preventative measures. Fool me once, but not twice, was the thinking.

As detailed in Chap. 1, the Tuskegee study involved deceiving poor African American males by telling them that if they agreed to be screened for syphilis, they would receive treatment. Instead, they received no treatment or inadequate treatment, and were even harmed, with African American healthcare providers lying to them, too. This time, aware of the Tuskegee history, African American males were not interested in hearing about any “voluntary” testing or screening programs conducted by mainstream medicine. Additionally, due to misinformation about the Tuskegee study that abounded throughout the 1970s (Reverby 2009), a large percentage of African Americans actually believed the U.S. government deliberately infected them with syphilis. Similarly, when HIV/AIDS began to proliferate through African American communities, there was suspicion that it was a “secret” genocidal virus the government cooked up to kill them, along with gay males. Misinformation about HIV/AIDS, complicated by the legacy of Tuskegee, became a “wicked problem”. As I discussed in Chap. 1, the situation became so bad, that Jones felt compelled by 1993 to release a second edition of *Bad Blood* with a new chapter entirely devoted to AIDS, in which he states (Jones 1993: ix):

> In this expanded edition of Bad Blood, I have traced the Tuskegee’s Study’s legacy in the age of AIDS. Briefly, I have shown why many blacks believe that AIDS is a form of racial genocide employed by whites to exterminate blacks, and I have examined how the Tuskegee Study has been used by blacks to support their conspiracy theory.

Even with funding for HIV/AIDS research in the African American community, research became more challenging because of new ethical guidelines for research, published by the National Commission for Protection of Human Subjects, which formed because of the Tuskegee study (see Chap. 1). These guidelines mandated protections for vulnerable populations in medical research, but major trust issues between African American patients, medical research, and medical institutions became barriers. For example, “[a]t the first CDC conference on AIDS and minorities in 1987, members of a black coalition caucus argued that the ‘black clergy
and church’ needed to assure African Americans that ‘AIDS testing and counseling initiatives are not just another Tuskegee tragedy being perpetrated on the black race’” (Reverby 2009). In fact, there was a valid belief in this community that the government was “giving them AIDS” because of the U.S. government’s failure to protect the public blood supply, which Shilts’ reveals in his book. Nonetheless, by 2010, the consequences were stunning; although African Americans represented approximately 12% of the U.S. population, they accounted for almost half (46%) of people living with HIV in the United States., as well as nearly half (45%) of new infections each year (CDC 2013). Among female adults and adolescents diagnosed with HIV infection in 2008, 65% were African American compared to 17% who were white and 16% who were Hispanic/Latino. Thus, the HIV incidence rate for African American women is nearly 15 times as high as that of white women.

**Band Width: Getting Shilts’ Story on Film**

Almost as soon as Shilts’ book was published, interest in purchasing the rights for a film began. Aaron Spelling, who was a long-time television producer, met with Shilts to pitch the film version to ABC television, and was turned down because of the content. Next, a producer with NBC, Edgar Scherick, purchased the rights to the book, but the project was put on hold for two years and then it was dropped because of the “gay content” (Michaelson 1993). Network advertisers did not want to support any program that featured homosexuals (Michaelson 1993). Spelling then purchased the rights again, but they were bought by HBO, which was not under the same pressure from advertisers. Bob Cooper, an executive at HBO recalled (Michaelson 1993):

> The day the project was dropped is the day we picked it up—immediately…in that it has a ticking clock…How does society cope with a huge crisis? Or not cope?…[It was] a great David and Goliath drama: little Don Francis and little Bill Kraus fighting every group, constituency, agency and being rejected.

To tackle the 630-page book and make it into a workable script, screenwriter Arnold Schulman delivered 17 drafts as there were continuous changes with directors, legal reviews, and Shilts’ reviews of the script. The first director was hired in April 1991—Joel Schumacher—who wanted to change the project into a documentary that was similar to PBS’ “The Civil War.”, which had just aired the previous year (Michaelson 1993). Nobody liked that idea. Next, director, Richard Pearce, who had worked on sensitive Civil Rights material with *The Long Walk Home* (1990) was promising, but left the project to work on the film *Leap of Faith* (1992) for Paramount (Michaelson 1993). The final director, who completed the project was Roger Spottiswoode, who made critical decisions about the content that made the film work. He recounts (Michaelson 1993):

> When Dick Pearce left, I moved in quickly…I knew it was out there; I knew the book. It’s an absolutely fascinating subject. A dramatic detective story, a story about politics, a morality
tale about how we all behaved and whether we behaved properly, which I don’t think we did. … We all have to accept some responsibility for the fact that for the first five years people in this country believed that for some reason this was a gay plague, that it was brought about by gay people, that it was their problem and that somehow it would go away.

HBO film projects, which I discuss more in Chap. 1, were never intended to be “made for TV” productions. Instead, the network’s independent films were produced using feature film quality and production standards. From the start of the project, the producers wanted an ensemble cast of well-known actors to “offset any reluctance that some viewers might have about AIDS and the movie’s predominantly compassionate portrayal of the plight of the gay community” (Michaelson 1993). Several feature film directors and A-list actors were contemplated, including Penny Marshall, (Michaelson 1993) who had directed *Awakenings* (1990), which I discuss in Clinical Ethics on Film (Rosenthal 2018). Actors discussed included Richard Gere (who plays choreographer Michael Bennet of “A Chorus Line”, who died of AIDS). Gere is heterosexual although there was tabloid speculation about his orientation. He was eager to join the cast, stating (Michaelson 1993):

As you know and I know, there is nothing wrong with being gay. Now if you start with that premise, the rest is all kid stuff and silliness, isn’t it?…And they beseeched me…There wasn’t really a part in there for me.

Although Gere was already booked up for months with other projects, he accepted the role as Bennet in a cameo, who in the film, gives money to the CDC to help fund research—potentially a nod to Rock Hudson (see earlier).

Shilts’ book does not revolve around any single figure as the main character, but screenwriter Schulman chose to focus the script around the CDC’s Don Francis, who shouts “How many dead hemophiliacs do you need?” at a contentious meeting with blood industry officials. Recalled Schulman (Michaelson 1993):

I made [Francis] the hero because here’s a man who had no other agenda. He worked in the field. If you want to stop an epidemic, you do this, this and this. And people’s toes get stepped on—’Too bad; we’re here to save lives.’ And suddenly he gets into this situation.

Matthew Modine was cast as Francis, who was praised for his work in *Memphis Belle* (1990). Modine had very clear memories of AIDS, stating (Michaelson 1993):

When I moved to New York, I was a chef in a restaurant, and to the best of my knowledge all the waiters are dead. They were some of the first to go before they called it gay-related immune deficiency. They died of colds? That was in ’79-’80-’81. If we think of ourselves as tribes, there’s a tribe of media people, a tribe of hospital people, a tribe of businessmen. Well, my tribe, the artistic tribe—actors, dancers and jugglers and storytellers—they’ve been decimated.

One character that was banned as a “focus” was so-called “Patient Zero” from the first epidemiological cluster study (see under History of Medicine), who many screenwriters may have wanted to emphasize. However (Michaelson 1993):

Shilts had already stipulated in his “deal memo” with HBO that the handsome young French Canadian airline steward Gaetan Dugas—better known as “Patient Zero” because [a large
number of the first infected men] found to have AIDS in the United States either had had sex with Dugas or with someone else who had had sex with him—not be “a major plot line.”

The first drafts of the script had been approved to focus, instead, on a number of public health characters, while later drafts of the script omitted unnecessarily “added” characters, such as any of the spouses of the public health officials to avoid the “Sissy Spacek problem” we see in films such as JFK (1991), where she plays the neglected wife of the prosecutor and merely detracts from the plot (Michaelson 1993). Thus, decisions were made to focus on the science and healthcare protagonists in the story—which is one reason this film can be used to teach healthcare trainees and students today. The film’s vast, all-star cast delivers more of a Robert Altman-style of direction—quick-paced, high quality (the stuff of 1976’s Nashville fame)—instead of a sappy 1970s disaster feel of an Irwin Allen’s style of direction seen in Earthquake (1974) or Airport 1975 (1975). The film version of Shilt’s book also mirrors the book’s chronological pace, featuring the work—not the personal lives—of: Don Francis, Mary Guinan (played by Glenne Headly), Selma Dritz (played by Lily Tomlin), San Francisco Director of Public Health, Merv Silverman (played by David Dukes), pediatrician, Art Ammann (Anjelica Huston, playing a female version), Marc Conant (played by Richard Jenkins) the key Pasteur Institute researchers, and Robert Gallo (played by Alan Alda), who was accused of research misconduct (see under History of Medicine). It also covers Bill Kraus (played by Ian McKellen), the San Francisco politician and activist, with only small glimpses of his personal life for 1993 viewers to understand the “family systems” aspects of gay male partnerships. Patients who were either instrumental in helping to fill in knowledge gaps in the early days of the epidemic, such as Dugas, transfusion-AIDS patient, Mary Richards Johnstone (played by Swoosie Kurtz), as well as a range of actors playing real characters from Shilts’ panorama of afflicted gay males who have now died. The film also discusses the tense battle over closure of the San Francisco bath houses, with Phil Collins appearing as one of the owners of these establishments. Ian McKellen, who plays Bill Kraus, recalled when his friend, Scottish actor, Ian Charleson (who starred in 1984’s Chariots of Fire), had died from AIDS in 1990 (Michaelson 1993), and was who he thought of when doing Kraus’ deathbed scenes in the same hospital as actual dying AIDS patients (Michaelson 1993):

I saw (him) in his last performance as Hamlet at the National Theatre, about two or three months before he died… I remember Ian when he was very weak at the end, putting all his energies into his body, sometimes very bright, and (other) times going away from you. … You know, you (wear the makeup) of the disease Kaposi’s sarcoma, and it’s just a bit of plastic. And just across the ward there are people who are marked for life, and now facing the possibility of dying. That’s when acting and life come right up close against each other.

Documentary Versus Docudrama

Shilts’ book spent three years in development as a film; from 1989 until 1991, the film went through multiple changes in direction. Schumacher recalled: “In the well-intentioned efforts to dramatize this (story), we have veered from journalism toward
fiction, and I think that this would be an immoral, irresponsible way to present the material” (Michaelson 1991). But Shilts didn’t want a documentary because he felt it would alienate much of the audience (Michaelson 1991). Schumacher was also contemplating having eye witness talking heads interspersed, similar to Warren Beatty’s masterpiece, *Reds* (1981).

There was also discussion as to whether the film should cover any part of Ryan White’s story, who had died in 1990—after the book was published. Shilts did not really cover White in the book, and instead, focused on Hudson’s death as a turning point. But White appears in the montage of AIDS victims after the film. Schumacher said in 1991: “When this innocent child died, I think everybody realized [AIDS] was something that could come into your own home” (Michaelson 1991).

By August 1991, creative differences in the direction of the film led to Schumacher leaving the project, and he signed on, instead to a “toxic L. A.” film called *Falling Down* (1993—I discuss the “toxic L. A.” genre of films in Clinical Ethics on Film). Schumacher had told HBO that he didn’t want to make a drama but a documentary, and so they parted ways. At that point, Spottiswoode was brought in, who had no problem with the docudrama form. He said (Michaelson 1993):

> I don’t think you should lie. I don’t think you should attack somebody who shouldn’t be attacked. And I don’t think you should intentionally portray a falsehood. However, to portray what you hope is the truth, you sometimes have to (alter) for clarity’s sake, for dramatic purposes. There are times you have to take certain liberties with details.

In the final script, key lines in Shilts’ book deliver the truth about early AIDS, such as the line delivered by Dr. Marc Conant: “You know damn well if this epidemic were killing grandmothers, virgins and four-star generals instead of gay men, you’d have an army of investigators out there.” Spottiswoode also used actual AIDS patients as extras in critical hospital scenes, and had Bill Mannion, chairman of the Shanti Foundation, visit the set to educate the crew about risks of working with extras who were people with AIDS (Michaelson 1993).

**Script Approval and Fact Checking**

Considering that Shilts was HIV-positive during this timeframe (prior to the development of protease inhibitors), getting his book translated onto the screen was a race against time, as he began to get sick around 1992. The film’s accuracy and quality were dependent upon Shilts’ availability to review and approve the final script. Screenwriter, Arnold Schulman, also did his own research and fact-checking when translating Shilts’ book to the screen. He met repeatedly with Shilts to discuss several facts and aspects of the script. He met several of the key figures he was writing about, including Francis, CDC doctors and researchers. Before writing about Gallo, Schulman also read up on reports of his scientific misconduct, which I discuss further below (see under History of Medicine). Schulman also reviewed other works about AIDS, which were published after Shilts, including Dominique Lapierre’s 1991 book, *Beyond Love* (Michaelson 1993). Ultimately, Shilts reviewed all of the drafts of the
script, and also insisted on scenes that accurately depicted the gay community’s buddy program, started by the GMHC, for example (Michaelson 1993).

**Synopsis**

*And the Band Played On* is a fairly literal screen adaptation of the 1987 book, which tracks a cross-section of the early AIDS epidemic theaters in chronological order: healthcare providers, researchers, patients, and public health officials on the front lines. It captures the most essential details of the 630-page book without falling victim to maudlin and unnecessary subplots. The film focuses on specific characters at the CDC, such as Don Francis; the work of Mary Guinan; as well as local San Francisco figures such as Selma Dritz and Marc Conant. It presents critical meetings that took place accurately, particularly the meeting in which the virus is finally labeled AIDS. The film does not cover the New York City theater of AIDS, or any of the content surrounding Larry Kramer and the GMHC. This film ages well, and can be used as a History of Medicine film about the early history of HIV/AIDS, which medical students frequently are not taught. It can also be taught as a research ethics film with respect to the discovery of HIV, and spends considerable time on NIH scientist Robert Gallo, played by Alan Alda. This film is also a public health ethics film, and illustrates one of the most egregious examples of ethical violations by healthcare providers who failed to warn patients of the risks of transfusion AIDS and who engaged in discriminatory practices by abandoning patients; research ethics misconduct with respect to translational research; and public health ethics violations with respect to protecting the public blood supply. With a tremendous cast of actors in both major and small parts, the film is gripping and fast-paced and makes a tremendous contribution to AIDS education. Finally, airing in 1993, it ends with scenes of one of the first AIDS quilt demonstrations and a moving montage of notable people and celebrities who had died from AIDS as of 1993, including Rock Hudson, Ryan White and Arthur Ashe.

**The Picture of AIDS in the Clinton Era: 1993**

In 1993, *And the Band Played On* premiered on HBO on September 11—a strangely ominous date that in eight years would completely redefine the United States, and become synonymous with catastrophic loss of lives. It’s important to note, however, that on September 11, 1993 the number of American civilians who died from AIDS was 57 times the number of civilian casualties on 9/11, not including the deaths from dust exposure (see Chap. 4). Yet the government response was different. As the *New York Times* noted [emphasis mine] when the film premiered (Michaelson 1993):
At a glance, one might surmise that the long journey from book to movie might have drained some controversial punch. After all, the Reagan Administration is long gone; the blood banks have been cleaned up...Meanwhile, the numbers keep piling up. The AIDS body count, or “butcher’s bill,” is the grim thread running through Shilts’ book. In July, 1985, the month the world learned that Rock Hudson had AIDS, the number of Americans with AIDS had surpassed 12,000 and the toll of dead was 6,079. Through the end of 1992, the Centers for Disease Control reported that 244,939 people in the United States had contracted AIDS, of whom 171,890 had died.

Let that sink in. But unlike 9/11 (conspiracy theories aside), those who contracted AIDS through the U.S. blood supply could literally say it was an “inside job” and the U.S. government actually had blood on its hands. By 1993, the politics in the United States had shifted and the Clinton era had begun, which promised progressive policies such as universal healthcare, with a proposed “Healthcare Security Act”, (see Chap. 4).

By this point, Randy Shilts was dying of AIDS, and completed his third book from his hospital bed (Schmalz 1993), entitled, Conduct Unbecoming: Lesbians and Gays in the U.S. Military, Vietnam to the Persian Gulf (Shilts 1993). Shilts referred to it as the “definitive book on homophobia.” By exposing the U.S. military’s treatment of homosexual service members, the film, And the Band Played On resonated. Clearly, thousands of heterosexual and pediatric deaths could now be traced to deep homophobia within the U.S. government, based on its initial response to “GRID”. Shilts’ book covered the history of persecution of homosexuals in the military, and became a bestseller at 700 pages. In 2014, Shilts’ book resonated with the film, The Imitation Game, which was about the treatment of Alan Turing, who is not only responsible for turning World War II around due to his code cracking, but who was shamefully discharged and treated by the British military with harmful hormone therapies for his homosexuality (Casey 1993).

This time, the President of the United States responded. Indeed, the opening act of the Clinton administration was to address “gays in the military”. Clinton had promised during the 1992 campaign to reverse military policy banning homosexuals from service. He kept his promise, and pushed for reform. Just 10 days after his inauguration, President Clinton announced his plan to change the policy, which was reported by the New York Times [emphasis mine] like this (Ifil 1993):

After days of negotiation and rancor in the military and Congress, Mr. Clinton temporarily suspended the formal discharge of homosexuals from the military and announced that new recruits would no longer be asked if they are homosexuals. He ordered the Pentagon to produce an order for him to sign by July 15 [1993]. …In the meantime, the military will continue discharge proceedings against avowed homosexuals or those it believes to be gay. While acknowledged homosexuals will not actually be ousted from the service, Mr. Clinton was forced to agree to a plan that will place them in the unpaid standby reserves – in effect, putting their military careers in limbo – and require that they petition for reinstatement if the ban is permanently lifted.

Mr. Clinton called his announcement today a “dramatic step forward”; it represented the first time a President had taken steps to aid gay men and lesbians in the armed services. But he acknowledged that he had yielded on important issues. “This compromise is not everything I would have hoped for, or everything that I have stood for, but it is plainly a substantial step in the right direction,” Mr. Clinton said during the first news conference of his Presidency,
which was entirely devoted to the question of homosexuals in the military and not the economic issues that Mr. Clinton has sought to emphasize.

Although this was not a complete lifting of the ban, the new policy would make a distinction between banning gay service members for “conduct” such as wanted, or unwanted homosexual acts, versus their sexual status or orientation: being a homosexual.

The New York Times explained the changes this way (Ifil 1993):

Questions about sexual orientation will be removed from the induction form; Homosexuality will no longer be grounds for outright discharge from the military; Court proceedings against those discharged for being homosexual will be delayed; Rules on sexual conduct will be explained to recruits; The Pentagon will draft an executive order banning discrimination against homosexuals.

On July 19, 1993—just 6 months after he was sworn in—President Clinton announced the official new policy on the treatment of homosexuals in the military, allowing them to serve so long as they kept their sexual orientation and preferences to themselves. This became known as the “Don’t Ask, Don’t Tell” policy (see further) that would continue until the Obama era in 2011. The new policy was formally signed on December 21, 1993. The next day, the second major Hollywood film about AIDS (following And the Band Played On) was released to a limited number of theaters: Philadelphia (1993), starring Tom Hanks and Denzel Washington. Philadelphia was essentially about “Don’t Ask, Don’t Tell” in the workplace, and was based on the 1987 true story of attorney, Geoffrey Bowers, who was fired because he was discovered to have AIDS due to visible Kaposi’s sarcoma. The attorney filed a wrongful dismissal case and sued his law firm, which became the first known lawsuit over HIV/AIDS discrimination (Navarro 1994). In the film, the plaintiff’s name is Andrew Beckett, played by Tom Hanks, who deliberately concealed he was gay and that he had AIDS. His lawyer, played by Denzel Washington, is a homophobic African American attorney who reluctantly takes on the case, rightfully locating it as a civil rights case. Ironically, Bowers’ case only settled in December 1993—just as Philadelphia was released (Navarro 1994). Bowers had died in September, 1987—while Reagan was still President, coinciding with the release of Shilts’ book. Bowers’ companion also died of AIDS in 1988, and court hearings on the case occurred between July 1987 and June 1989.

It is not known if Shilts’ ever saw Philadelphia, as he died February 17, 1994—but did live to see the policy “Don’t Ask, Don’t Tell” which his work helped to inspire. Bowers said in court: “In light of the fact that I was dealing with my AIDS and my Kaposi’s sarcoma, I merely felt as though they had taken the last thing in the world that meant anything to me” (Navarro 1994). When Philadelphia was released, before the Bowers case was resolved, his surviving family members sued Scott Rudin, the producer of Philadelphia as the film duplicated so much of the Bowers’ case and family experience without their consent to use their case for a film. They settled in 1996 as Rudin conceded that much of the script was based on public records of the case, although he had also interviewed the family and lawyers. Ultimately, Bowers case, Philadelphia, and Shilts’ third masterpiece on gay issues,
Conduct Unbecoming, highlighted the intersection between gay civil rights and AIDS discrimination. There were a host of HIV/AIDS films that began to burst forth around this time frame, including the cinema-verite, “reality” documentary, Silverlake Life (1993), filmed by the partner of a dying man with AIDS, about their everyday lives in Los Angeles (Ehrenstein 1993).

Don’t Ask, Don’t Tell

The phrase “Don’t Ask, Don’t Tell“ was coined by a military sociologist, Charles Moskos in 1993. No one could foresee on September 11, 1993—the day HBO aired And the Band Played On—how important “Don’t Ask, Don’t Tell” would become to national security eight years later, in which the American military would become embroiled in two wars as a result of 9/11. In the post-9/11 years, the U.S. military would be stretched beyond the capacity of its all-volunteer military. It would be highly dependent on its gay service members, who would go on to fight in Afghanistan and Iraq.

Reversing the ban on homosexuals in the military occurred during one of the most peaceful times in the twentieth century, as well as the most hopeful. Initially, President Clinton wanted to completely lift the ban, but once he was inaugurated, there was considerable resistance to that plan by his Joint Chiefs and his Democratic-led Congress; Barney Frank, who would later come out as the first openly gay congressman, actually voted to keep the ban. The argument then was that openly gay service members would “undermine ‘unit cohesion’ and threaten combat effectiveness” (De La Garza 2018). After a six-month review, Clinton would go for a compromise, which meant that service members could no longer be asked about their sexual orientation, and they were not required to disclose it. However, they could still be dismissed if they chose to disclose it, which “prompted outrage from many gay rights advocates who argued the new policy was simply a repacked version of the old ban that was put into place” (La Garza 2018). In fact, the debate in 1993 resembles many of the same issues surrounding the controversial ban on transgender troops in the Trump Administration. However, given the intense homophobia that still prevailed in 1993, on the heels of And the Band Played On and Philadelphia, “Don’t Ask Don’t Tell” was an important bridge to the future, particularly in a timeframe when there was still no sign of a cure for AIDS.

For example, in August 1992, a Marine Corps chaplain wrote a position paper that stated: “In the unique, intensely close environment of the military, homosexual conduct can threaten the lives, including the physical (e.g. AIDS) and psychological well-being of others”(Schmitt 1992). In 1993, Senator Strom Thurmond stated to a gay service member when he toured a military base—to applause no less (De La Garza 2018): “Your lifestyle is not normal. It’s not normal for a man to want to be with a man or a woman with a woman.” He then asked the service member if he ever sought out medical or psychiatric aid (De La Garza 2018). Around the same time, a Navy Commander stated: “Homosexuals are notoriously promiscuous” (a fact
made clear in Shilts’ book) declaring that heterosexuals would feel uncomfortable in shared quarters or showers (Schmitt 1993). There were noted Republicans who favored lifting the ban, including Dick Cheney (Secretary of Defense in the Bush 41 Administration), and Barry Goldwater, who wrote an opinion piece in 1993 where he stated that “You don’t have to be straight to shoot straight” (Bull 1998).

Despite President Clinton’s promise to completely lift the ban, in 1993 it was indeed a bridge too far, but the policy opened the door to at least open dialogue surrounding gay Americans. “There was a vast sea change of opinion about this over a decade and a half, and a big part of that was keeping the dialogue going and presenting incredibly patriotic individuals who were serving openly” (De La Garza 2018). In 1994, 45% of Americans wanted to keep the ban, but by 2010, only 27% wanted the ban. On December 21, 1993, Military Directive 1304.26 was issued with the “Don’t Ask, Don’t Tell” policy codified:

E1.2.8.1. A person’s sexual orientation is considered a personal and private matter, and is not a bar to service entry or continued service unless manifested by homosexual conduct in the manner described in subparagraph E1.2.8.2., below. Applicants for enlistment, appointment, or induction shall not be asked or required to reveal whether they are heterosexual, homosexual or bisexual. Applicants also will not be asked or required to reveal whether they have engaged in homosexual conduct, unless independent evidence is received indicating that an applicant engaged in such conduct or unless the applicant volunteers a statement that he or she is a homosexual or bisexual, or words to that effect.

Gay advocates continue to argue that “Don’t Ask, Don’t Tell” was only a marginal step forward (De La Garza 2018). A 1993 RAND report (Rostker et al. 1993) actually supported lifting the ban, but the report was apparently shelved. The argument was that privacy about being gay was not considered the same as serving openly gay, as gay service members could still be discharged for demonstrating homosexual behaviors, while the same culture of harassment of gay service members persisted. For example, if a service member didn’t tell, he was still vulnerable for being “outed” if his license plates were spotted at a gay bar, for example (De La Garza 2018).

Military Directive 1304.26 went into effect February 28, 1994—11 days after Shilts had died of AIDS, and two days after the first anniversary of the 1993 World Trade Center Bombing of February 26, 1993, an event that foretold September 11, 2001 (Wright 2006). It remained the official policy of the U.S. Department of Defense until it was finally repealed in 2011 by the Obama Administration, which completely lifted the ban once and for all—in the 30th year of AIDS, when there were close to 70,000 gay service members. President Obama said on the day the ban was lifted: “As of today, patriotic Americans in uniform will no longer have to lie about who they are in order to serve the country they love” (De La Garza 2018). By 2019, Mayor Pete Buttigieg, an openly gay veteran, who honorably served in the post-9/11 wars, announced himself as one of the Democratic Presidential candidates for the 2020 Presidential election, and was open about being married to a male, in light of the Supreme Court ruling that made same sex marriage the law of the land in 2015. He went on to win the 2020 Iowa Caucus, Shilts’ home state.

Although “Don’t Ask Don’t Tell” seemed to many at the time to be an odd “first battle” of President Clinton’s Administration, in the context of delayed action on
AIDS in the 1980s due to homophobia, his initial gesture to begin to integrate gay Americans into the military was symbolic of gay integration into American life overall, which was necessary in the next phases of battling AIDS. Even President Clinton did not foresee that his bridge would lead 26 years later to an openly gay veteran as candidate for President in 2020.

Ultimately, the premise of “Don’t Ask, Don’t Tell” and continuing HIV/AIDS discrimination in housing, the workplace, and elsewhere, would form the basis for the 1996 *Health Insurance Portability and Accountability Act* (HIPAA), which President Clinton would sign the same year protease inhibitors would be made available (see under History of Medicine). When it comes to AIDS, the most important aspect of HIPAA would be its Privacy Rules, which would take effect April 14, 2003 (see under Healthcare Ethics Issues)—only three weeks after thousands of troops (many gay) would head to Iraq. Being fired for concealing AIDS in the workplace—as told in the *Philadelphia* story—would no longer be possible, as Protected Health Information (PHI) could no longer be shared with employers or anybody else without explicit permission of the patient.

**History of Medicine Context: From “GRID”-Lock to Cocktails**

The purpose of teaching *And the Band Played On* in the healthcare ethics context is to use the early history of AIDS as a case study to primarily demonstrate violations of the Principle of Non-Maleficence. However, many educators may be using the film to simply teach history of medicine, or as part of the social history in LBGT studies. This section will focus on the early medical history, research and treatment of AIDS from 1981 until 1996, when protease inhibitors were approved. This section will review key HIV/AIDS practitioners and researchers during this timeline; the battle to screen the blood supply; the first era of HIV testing and treatment; and finally, the cocktail era and beyond.

**The First Paper on AIDS: Michael Gottlieb**

Imagine being a new assistant professor in the Department of Medicine at UCLA, authoring the first scientific paper on AIDS before it was labelled either “GRID” or “AIDS”, as well as close to 50 more publications in high-end journals; getting an NIH grant worth 10.5 million dollars to start an AIDS research and treatment program at your institution; having Rock Hudson as your patient, and securing a $250,000 gift from him for AIDS research; co-founding the first major AIDS research foundation (amFAR—see earlier), and then not getting tenure because your Department Chair, Dean, and other colleagues just don’t like you (Hillman 2017; Shilts 1987). That
is the story of Michael Gottlieb, who published the first paper on AIDS on June 5, 1981, in *Morbidity and Mortality Weekly Report* (CDC 1981a) as well as the first major scientific paper on AIDS in the *New England Journal of Medicine* (Gottlieb et al. 1981). The CDC selected his first paper as one of their most important historical articles “of interest” in 1996 on the occasion of the journal’s 50th anniversary (CDC 1996). In 2012, the *New England Journal of Medicine* selected his next paper as one of the most important publications in the journal’s over 200-year history (Hillman 2017).

Michael Gottlieb found himself, like several other physicians at that time, treating the first known cases of AIDS in the United States at UCLA in November of 1980 (Shilts 1987; Gottlieb 1988). What distinguished Gottlieb as the “discoverer of AIDS” was his diagnostic prowess in identifying it as an entirely “new disease” based on the first five patients he saw who succumbed to pneumocystis carinii pneumonia. The first one he saw presented with out-of-control *Candida albicans* or thrush (Hillman 2017). According to Gottlieb: “The case smelled like an immune deficiency. You don’t get a mouth full of *Candida* without being immune deficient” (Hillman 2017).

Gottlieb was born in 1947 and graduated from the University of Rochester medical school in 1973; he identified immunologist John Condemi as his mentor, and did a fellowship at Stanford University where he focused on the new field of cellular immunology and T-lymphocytes—his area of interest (Hillman 2017). He was hired in July 1980 at UCLA with a modest start-up lab package (Hillman 2017) to carry on with his burgeoning career in immunology research. When one of the UCLA Fellows came to him about a patient with unusual symptoms (weight loss and thrush, and later pneumonia). Gottlieb’s work in immunology informed his idea to request a work-up of the patient by looking at his immune system because the patient’s diseases appeared to be only known in patients with compromised immunity. Gottlieb’s work-up allowed him to spot a CD4 T-lymphocyte abnormality, explaining the opportunistic infections ravaging the patient. Gottlieb began to note this same phenomenon in four other patients in a short time span—all homosexuals. Gottlieb felt this was a new phenomenon. He contacted the editor of the *New England Journal of Medicine* to discuss whether the journal would be interested in publishing on the new phenomenon, and the journal editor suggested that he first report it to the CDC through its weekly journal, *Morbidity and Mortality Weekly Report* (MMWR) and that his journal would be pleased to review his submission. So Gottlieb wrote the first known paper on AIDS, entitling it “*Pneumocystis* Pneumonia Among Homosexual Men in Los Angeles”; it was published as “*Pneumocystis* Pneumonia—Los Angeles” on June 5, 1981, forever marking that date as the official birthday of the AIDS epidemic. His biographer notes (Hillman 2017):

> Ultimately, Dr. Michael Gottlieb’s discovery of AIDS and its underlying abnormality of cellular immunity was the product of happenstance and a mind willing to consider new possibilities. Unlike others who saw only what they expected to see or who tried to pigeonhole their findings into an ill-fitting, existing medical construct, Gottlieb made the necessary intellectual leap.
On the 30th anniversary of his first publication, Gottlieb recalled (SF AIDS Foundation 2011):

It was in 1981 when I saw the first patients that we reported in the CDC’s Morbidity and Mortality Weekly Report. I remember those four men more vividly than patients I saw yesterday. I saw the worry on their faces and witnessed their courage and patience as they realized that we had no idea of what their illness was or how to treat it. I knew right away that I would be in it for the long run….We should not forget that the Reagan administration refused to even acknowledge, much less prioritize AIDS, setting back the nation’s response to the epidemic by a decade.

The June 5, 1981, paper in MMRW would be followed by a July 3, 1981, paper on Kaposi’s sarcoma and pneumonia co-authored by Linda Laubenstein (see further), Gottlieb and many others entitled: “Kaposi’s Sarcoma and Pneumocystis Pneumonia among Homosexual Men—New York City and California” which reported on both conditions showing up in gay male communities in San Francisco, Los Angeles and New York City.” The July MMRW paper was picked up by the New York Times (Altman 1981) at which point the term “Gay-Related Immune Deficiency” (GRID) was first used in mainstream reports, as discussed earlier. The July 3rd article would be followed by the first CDC cluster study discussed further on, emphasizing the disease was spreading sexually among gay males. Gottlieb’s New England Journal of Medicine article followed on December 10, 1981, entitled: “Pneumocystis carinii Pneumonia and Mucosal Candidiasis in Previously Healthy Homosexual Men—Evidence of a New Acquired Cellular Immunodeficiency” (Gottlieb et al. 1981). As the first medical journal publications emphasized the epidemic in the gay male patient population, the new disease would be called GRID within the medical community, which damned future heterosexual AIDS patients, too.

In 1981, UCLA was not interested in this new “gay-related” disease, and did not want to be known as an institution that treated it. Instead, it was vying for recognition as a major transplant center. Notwithstanding, as a result of his first publications, Gottlieb became the “go to” source for any journalist covering AIDS (including Shilts at the time) because he had essentially become the “physician of record” on this new disease. Gottlieb was also invited to major conferences all over the world, and was essentially living the type of life one would expect to see from a senior expert in a field—such as Robert Gallo (see further). But Gottlieb was living the senior expert’s life prior to tenure, when he was only 33 years old. In 1983, Gottlieb was awarded half of a California state-funded grant of $2.5 million (1.25 million was provided each to UCSF and UCLA) for an “AIDS Clinical Research Center” for which he was named director. The California grant was perceived by UCLA’s Department of Medicine brass as a “political grant” because it was a line item in its state budget; the state essentially asked Gottlieb to submit a proposal so they could give him the money, demonstrating at least some commitment to AIDS on the part of the state legislature, which was burdened with a significant proportion of cases. But as his notoriety in AIDS rose, it was rocking the boat in his department, as competitive colleagues began to resent him—and began to complain about him.
The running complaint was over authorship squabbles and being cut out of funded research.

The boat was about to get rockier; in July 1985, a month after the fourth anniversary of his MMWR paper, Gottlieb was called by the personal physician to actor Rock Hudson (see earlier), who asked him to come and see her patient because she suspected Hudson might have AIDS due to some unusual spots she thought might be Kaposi’s sarcoma. Apparently, the spots were first noticed by First Lady Nancy Reagan who was hosting Hudson at an event at the White House (Hillman 2017). When Gottlieb confirmed that Hudson had AIDS, he became his physician of record and arguably, may have succumbed to “VIP Syndrome” (see under Healthcare Ethics Issues). As discussed earlier, once Rock Hudson revealed that he was dying of AIDS, it became one of the major media stories of the decade, and Gottlieb’s fame and star power rose even higher, resulting in his befriending of Elizabeth Taylor with whom he co-founded NARF (see earlier), which eventually became amFAR (see earlier). But within Gottlieb’s academic home institution, he was labelled “star struck” while his academic duties and priorities were questioned (Hillman 2017). One of the reasons cited for Gottlieb’s institutional political problems was the Rock Hudson gift for “AIDS research”. Gottlieb used it to start a foundation outside UCLA because he had concerns about whether Hudson’s money would be properly allocated to AIDS research inside UCLA (Hillman 2017). However, Gottlieb was still the Golden Goose for his institution in that he secured a federally funded NIH grant for 10.3 million in 1986, which was an astronomical amount of extramural funding for an assistant professor at that time.

The NIH grant was indeed competitive and comprised an awarded contract by the National Institute of Allergy and Infectious Diseases (NIAD) to several institutions for an AIDS Clinical Trials Group (ACTG) to test potential therapies for HIV, which included Gottlieb’s involvement in testing AZT. (The first grants awarded were for “AIDS Treatment and Evaluation Units”—or ATEUs, which is what Gottlieb started at UCLA.)

While it is predictable that one of these coveted ACTG awards would go to the man who “discovered” AIDS at UCLA, wrote the first papers, and authored numerous publications on it, it is also inconceivable that such a grant was not supported by Gottlieb’s institution. But it wasn’t—which reflects how work on AIDS was valued at the time—not very much. The stigma and disdain for AIDS research, which characterized most of the 1980s, is one of chief themes of And the Band Played On, and followed a host of early AIDS clinical researchers, including Linda Laubenstein (see further), whose colleagues thought she was foolish to waste her time on AIDS patients. A retrospective on Gottlieb’s career in the American Journal of Public Health (Gottlieb et al. 2006) reported:

Part of the problem, said Gottlieb, was that the UCLA Medical Center aspired to develop cardiac and liver transplant programs, and the physicians feared that if the hospital became too well known for AIDS, transplant patients might stay away. They also foresaw that there would ultimately be a lot of AIDS patients without good health care coverage. AIDS loomed as a threat to the well-being of the hospital and Gottlieb, so publicly and professionally identified with the disease, was becoming a nuisance.
Gottlieb’s institution refused to allocate appropriate office or lab space for his NIH grant. Typically, a grant of that size requires the institution to guarantee that there will be sufficient space, personnel and resources devoted to the Principal Investigator (PI), in order to house the grant and benefit from the “indirect costs”. In Gottlieb’s case, however, UCLA did not offer him sufficient resources and forced him to set up a lab off-campus at the local Veteran’s Association hospital with ancient facilities, making it even more difficult for him to fulfill his obligations on the grant as well as clinical care duties. Ultimately, Gottlieb’s notoriety in HIV/AIDS publications and AIDS advocacy outside of his institution created political problems for him inside his institution. Despite clearly meeting the criteria for tenure based on his scholarly productivity and extramural funding, his Chair refused to support his candidacy for associate professor with tenure. Gottlieb did not attempt to pursue any appeals process that was undoubtedly available to him, nor were other L.A.-based institutions interested in having Gottlieb transfer his research and grant over to them (Hillman 2017) once they spoke to his Chair. So the man who discovered AIDS at UCLA in 1981 resigned in 1987 when he realized he would not get tenure. All of this played out the very same the year And the Band Played On was published, which prominently featured Gottlieb. Between 1981 and 1987 Gottlieb was author of over 50 scholarly publications on HIV/AIDS. One member of his tenure and promotion committee, who was interviewed over 35 years later and still at UCLA (Hillman 2017), recalls the tenure deliberations were split between two factions—some who thought Gottlieb met the criteria, and some who insisted he was not “academic material”, acknowledging that in hindsight, fear and paranoia over AIDS may have been an underlying factor in a lack of support for Gottlieb (Hillman 2017). Indeed, Gottlieb’s biographer was given fuzzy reasons from Gottlieb’s former superiors for being denied tenure, such as not being a “serious enough” academic due to his celebrity/VIP patients, which also included pediatric AIDS activist Elisabeth Glaser (see further) Clearly, these reasons do not hold up to professional ethical standards and scrutiny today. Gottlieb’s resignation was an ugly episode, covered by the Los Angeles Times. It read in part (Nelson 1987):

Michael S. Gottlieb, the UCLA immunologist who in 1981 first reported cases of the mysterious disease now known as AIDS has resigned his full-time university post because he said he could not gain tenure.

“The climate at UCLA was not supportive of my academic advancement. It got too difficult to fight the disease and the system at the same time,” Gottlieb, 39, said in an interview this week. “By ‘the system,’ I mean the system that was resistant to facilitating research.”

Dr. Roy Young, acting chairman of the department of medicine, disputed Gottlieb’s account of why the celebrated researcher left. He said Gottlieb had “conflicts” with some colleagues and there were periods when he was not “research-wise.” Young would not elaborate.

He said Gottlieb resigned the middle of this month, before an academic committee had reached a decision on his promotion to tenured status, which confers a permanent appointment on the recipient.

Gaining tenure on UCLA’s medical faculty is a highly competitive hurdle for young physicians who must try for a limited number of new openings each year. Another potential
obstacle, say doctors who have had the experience, can come from already tenured faculty members who, because of personality conflicts or professional jealousy, may try to slow the advancement of a junior physician, especially one who has gained widespread recognition.

Last summer, Gottlieb became the principal investigator on a $10-million project awarded to UCLA’s AIDS treatment evaluation unit by the National Institutes of Health to test new anti-AIDS drugs. The study, to continue for five years, will not be affected by Gottlieb’s resignation.

Of note, Gottlieb eventually parted company with amFAR, too, when he and Krim did not see eye to eye. Gottlieb went into private practice (Gutierrez 2011) and remained an adjunct faculty member at UCLA in a clinical appointment.2 Gottlieb’s snubbing by his colleagues was a familiar narrative for early AIDS practitioners, which Linda Laubenstein experienced, too, when she was treating AIDS in her New York-based institution.

New York State of Mind: Linda Laubenstein

As Gottlieb was encountering pushback at UCLA over AIDS, hematologist/oncologist, Linda Laubenstein, was experiencing similar pushback—literally—at New York University Medical Center, where she was one of the first physicians in 1979 to begin treating the rare cancer, Kaposi’s sarcoma, in the first cluster of New York City gay males with AIDS. She partnered with her colleague, Alvin Friedman-Kien, a dermatologist, to deal with the onslaught of cases; Friedman-Kien was a co-author on the July 3rd MMRW paper as well (see earlier). Her first patients would present with enlarged lymph nodes and generalized rashes, and Kaposi’s sarcoma lesions. By May 1982, Laubenstein had treated 62 patients with Kaposi’s sarcoma (Lambert 1992), which was significant, considering it was an otherwise rare cancer, but 1 in 4 known AIDS patients was a patient of Laubenstein’s at that time (Larsen 2015).

Laubenstein was a polio survivor and was an outspoken paraplegic practitioner in a wheelchair, who fought for adequate resources to treat her AIDS patients, which included the famous “patient zero”, Gaetan Dugas (see further). Her patients and colleagues who knew she was a fighter for her patients called her a “bitch on wheels” (Gordon 1993). Laubenstein is featured in Shilts’ book; the character of “Dr. Emma Brookner”—the female paraplegic doctor character in Larry Kramer’s “The Normal Heart”—is based on her. Julia Roberts was cast in the role for the HBO film version.

2Three years later, Gottlieb was also the subject of a 1990 reprimand from the California Medical Board for writing narcotic prescriptions for Elizabeth Taylor under a patient alias (a common practice for celebrity patients pre-HIPAA). But based on the historical record, it appears this episode had nothing to do with his tenure decision as it surely would have surfaced as a reason when the principals involved were interviewed 35 years later. The complaint was not filed until 1989, but does relate to prescriptions written between 1983 and 88—spanning much of the time Gottlieb was still at UCLA (Ellis 1990; Associated Press 1994).
Laubenstein was the first AIDS practitioner to call upon the gay community to practice abstinence, and advocated for closing the gay bath houses (Lambert 1992). Laubenstein was the doctor of Kramer’s lover, who had succumbed to AIDS, and Kramer’s portrayal of her in “The Normal Heart” remains a memorial to her dedication.

In 1983, well before amFAR, Laubenstein co-founded the Kaposi’s Sarcoma Research Fund in 1983, and convened with Friedman-Kien, the first national medical conference on AIDS, which was held at New York University (Harvey and Ogilvie 2000). She and Friedman-Kien edited the conference proceedings, which were published in JAMA in 1984 as: “AIDS: The Epidemic of Kaposi’s Sarcoma and Opportunistic Infections” (Smilack 1984).

By 1989, as the social stigma of AIDS began to affect housing and employment, she helped to found a non-profit organization called Multitasking, which was an employment service for AIDS patients, since so many lost their jobs—and also their health insurance. Laubenstein, essentially, was not just an AIDS practitioner, but tried to address the wider social disparities because so few practitioners were speaking out for their marginalized patients. Like Gottlieb, she eventually left NYU for private practice where she had more autonomy to exclusively treat AIDS patients when many physicians refused to see them. Unlike Gottlieb, Laubenstein was in a clinical appointment and so tenure was not the issue, but being able to see and treat AIDS patients the way she wanted to as a practitioner without pushback. She was known for making house calls in her wheelchair, or meeting patients at the emergency room at all hours of the night.

Laubenstein’s own health was poor; because of post-polio syndrome, her lung capacity was compromised, and she eventually needed a ventilator and had difficulty weaning from it. Her death at age 45 in 1992 was due to a heart attack that was sudden and not foreseen. Ironically, she never lived to see the era of protease inhibitors, but some of her patients survived on AZT long enough to transition. At the time of her death, Kramer was close to a production agreement of “The Normal Heart” with Barbra Streisand, who would have played the Laubenstein-Brookner part, had the deal gone through. That particular deal never materialized; however, in the 1993 film, Philadelphia (discussed earlier), the female physician character who demonstrates compassion and fearlessness is likely a nod to Laubenstein, too. Laubenstein’s colleague, Friedman-Kein was a medical advisor on the “The Normal Heart” and she was the inspiration for the character (Driscoll 2011). Currently, there is a named award for Laubenstein (New York State Health Department 2020), and she is also noted for establishing some of the first clinical practice guidelines on HIV/AIDS.

The CDC Cluster Study and Gaetan Dugas

The biggest controversy in And the Band Played On surrounds AIDS patient, Gaetan Dugas, who was labelled “Patient Zero” in an early cluster study. Several critics
suggest that Shilts maligned Gaetan Dugas by (a) revealing his actual name in the book when Shilts was informed of it by the cluster study authors; and (b) suggesting Dugas maliciously and knowingly infected his lovers. This perception is unfortunate and misguided, but a 2016 paper in *Nature* (Worobey et al. 2016) vindicated Shilts’ reporting.

In June 1982, the CDC published an epidemiological study of the first cluster of early AIDS patients seen in California (CDC June 18, 1982; CDC 1982). The 1982 paper referenced one “non-Californian” (who was Gaetan Dugas) with KS as part of the cluster. No mention of him as “Patient 0/Zero” was made in the 1982 CDC paper.

This was followed by a much more comprehensive write up of the cluster study in 1984 (Auerbach et al. 1984).

The 1984 analysis of that same cluster centered around an *index patient* in the paper’s “Fig. 2.1”—a diagram of contacts (called a sociogram), placing “0” in the center of the sociogram (the Key reads: “0 = Index Patient”) who was connected to 40 patients either through primary, secondary or tertiary connections, and then the sociogram labels all sexual contacts in accordance with the “sequence of onset” of symptoms. Of note, index patients are routinely called “Patient 0/[Zero]” in infectious disease contexts. The 40 patients in Auerbach et al.’s sociogram are labelled by geographic location as follows: NY 1 through NY 22; LA 1 through LA 9; FL 1 through FL 2; GA 1 through GA 2; PA 1; NJ 1; SF 1; and TX 1. NY 1, for example, was the first New York contact in New York City to get sick, while NY 21 was the 21st contact in New York City to get sick. A verbatim description of the sociogram reads (Auerbach et al. 1984):

> Sexual contacts among homosexual men with AIDS. Each circle represents an AIDS patient. Lines connecting the circles represent sexual exposures. Indicated city or state is place of residence of a patient at the time of diagnosis. “0” indicates Patient 0 (described in text)

In this analysis, the authors had interviewed 248 patients; contact-tracing revealed that 40 were all connected through sexual contact to the Index patient, who they describe as “Patient 0” in the text of the paper (This index patient was the same “non-Californian” referred to in the 1982 paper.). The Index patient was later revealed to Shilts to be Gaetan Dugas—three years after he was deceased in a pre-HIPAA age. In explaining the Auerbach 1984 study in his book, Shilts’ writes: “At least 40 of the first 248 gay men diagnosed with GRID in the United States, as of April 12, 1982, either had had sex with Gaetan Dugas or had had sex with someone who had.” (Shilts 1987: 147). This was a completely accurate reporting of the 1984 cluster study paper in 1987, when the book came out, and as of this writing, it remains true that the 40 patients in that cluster were connected through sexual contact.

Dugas was a Canadian flight attendant; he was a real study subject in the first cluster study that definitively linked HIV to sexual contact. He was correctly identified in 1982 by CDC investigators as a non-Californian. Dugas died from AIDS in March 1984, just when the 1984 Auerbach et al. paper was published. Shilts’ descriptions of Dugas as Patient Zero and a frequent visitor to bath houses led to a misperception that Dugas brought AIDS to North America, which was never
concluded in any empiric study, nor was this ever definitively stated by Shilts. Shilts does promote the idea that Dugas spread the disease carelessly, which was based on Shilts’ interpretation of his interviews and notes with CDC investigators.

But years of questions about Dugas led to a reanalysis of data by a lead investigator at the University of Arizona (Worebey et al. 2016). The reanalysis found that the CDC’s initial labelling of Dugas was “O” for “Outside-of-California”, and he was patient number 057, for being the 57th case of AIDS reported to the CDC. When the cluster study was written up in 1984 to describe that 40 of the men were sexually connected, the O for “Outside” was misread as 0 for “Zero”, and Dugas was improperly labelled the Index Patient in the paper’s analysis of the cluster study. Accordingly (Worebey et al. 2016):

Before publication, Patient ‘O’ was the abbreviation used to indicate that this patient with Kaposi’s sarcoma resided ‘Out(side)-of-California.’ As investigators numbered the cluster cases by date of symptom onset, the letter ‘O’ was misinterpreted as the number ‘0,’ and the non-Californian AIDS patient entered the literature with that title. Although the authors of the cluster study repeatedly maintained that Patient 0 was probably not the ‘source’ of AIDS for the cluster or the wider US epidemic, many people have subsequently employed the term ‘patient zero’ to denote an original or primary case, and many still believe the story today.

According to Tara Smith (Smith 2016).

When we think of Dugas’s role in the epidemiology of HIV, we could possibly classify him as, at worst, a “super-spreader”—and individual who is responsible for a disproportionate amount of disease transmission. Dugas acknowledged sexual contact with hundreds of individuals between 1979 and 1981—but his numbers were similar to other gay men interviewed, averaging 227 per year (range 10-1560)…Dugas worked with researchers to identify as many of his partners as he could (~10% of his estimated 750), as the scientific and medical community struggled to figure out whether AIDS stemmed from a sexually-transmitted infection, as several lines of evidence suggested…

The media then extended Shilts’s ideas, further solidifying the assertion that Dugas was the origin of the U.S. epidemic… The New York Post ran a huge headline declaring “The Man Who Gave Us AIDS.” Time magazine jumped in with a story called ‘The Appalling Saga Of Patient Zero.” And 60 Minutes aired a feature on [Dugas, describing him as] “One of the first cases of AIDS…”

It remains unclear whether Shilts distorted his notes about Dugas from CDC sources, or reported facts and concerns about Dugas contemporaneously, in a timeframe where facts were very difficult to validate. Worobey et al. note this about the 1984 paper (Worobey et al. 2016):

Reports of one cluster of homosexual men with AIDS linked through sexual contact were important in suggesting the sexual transmission route of an infectious agent before the identification of HIV-1. Beginning in California, CDC investigators eventually connected 40 men in ten American cities to this sexual network [which included Dugas]. Thus, while [Dugas] did link AIDS cases in New York and Los Angeles through sexual contact, our results refute the widespread misinterpretation that he also infected them with HIV-1.

Thus, the 1984 sociogram is still accurate from the standpoint of connecting who had sex with whom, but Dugas was not the index case; the first case brought to the
CDC’s attention is labelled on the sociogram as “NY 3”, of which Dugas was a primary contact (Worebey et al. 2016).

As for Shilts’ descriptions of Dugas’ sexual activities, it was based on CDC sources, and their own interviews with Dugas. Dugas was very promiscuous, but exhibited typical behaviors for a sexually active gay male at the time who frequented the bathhouses. In 2013, video of Dugas surfaced that shows Dugas in March 1983 at an AIDS forum and panel hosted by AIDS Vancouver, asking questions that suggested he was indeed not practicing safe sex because of the absence of any clear HIV tests or guidelines for informing his lovers (AIDS Vancouver 2013). Dugas was not unique, and representative of hundreds of AIDS patients at the time. Moreover, contemporaneous minutes exist from June 20, 1983, surrounding AIDS Vancouver’s concerns about Dugas’ continued unsafe sexual activity (AIDS Vancouver 2013). Dugas’ final primary care doctor in Vancouver, Brian Willoughby, also stated in 2013 that he met Harold Jaffe from the CDC (co-author on the 1984 paper), who specifically told him that the CDC had identified Dugas as “patient zero” for the first cluster of cases they investigated in the U.S (AIDS Vancouver 2013).

Thus, historical retribution surrounding Shilts’ handling of the Dugas content does not consider: (a) validity limitations; (b) confidentiality limitations in infectious disease that had been long established; (c) the fact that there were no confidentiality rules applied to deceased patients in 1984; and (d) retrospective data or re-analyses of early epidemiological data that would not be clear until 29 years after the book was published (McNeil 2016).

In 2017, William Darrow, co-author of the 1984 paper and a source for Shilts, provided a retrospective analysis of Shilts’ reporting for And the Band Played On. He states (Darrow 2017):

The authors of at least a half-dozen books have addressed Randy’s decision to identify Patient 0 as Gaetan Dugas, while the co-authors of a book published three years earlier [when Dugas was alive] chose to use a pseudonym. In Chap. 5 (“The Clusters”) of The Truth About AIDS, Fettner and Check described a patient diagnosed with Kaposi’s sarcoma known to Drs. Linda Laubenstein and Alvin Friedman-Kien “who traveled a lot for a Canadian company. Call him Erik” (p. 85). After giving a lecture to physicians in San Francisco, Dr. Friedman-Kien was able to speak with Erik and placed a telephone call to his office in New York City shortly afterwards. “Linda,” he reportedly said, “I’ve located our Typhoid Mary.”

Darrow clarified that the 1984 paper’s sociogram reflects eight AIDS patients who slept with Patient Zero directly, and another eight patients who had sex with at least one of Patient Zero’s partners, which came to 16 (Darrow 2017). The rest of the contacts shown in the paper’s sociogram had tertiary contact, meaning they had sex with the partner of a partner of someone who had sex with Dugas. With respect to Shilts’ sentence [emphasis mine]: “Whether Gaetan Dugas actually was the person who brought AIDS to North America remains a question of debate and is ultimately unanswerable.” (Shilts 1987: 439), Darrow responded this way (Darrow 2017):

The question was answered by Worobey and colleagues who showed that Patient 0 was not the person who brought AIDS to North America. The suggestion that Mr. Dugas was the first North American case did not emanate from any member of the CDC Task Force.
Darrow also clarified the following about the 40 sexually connected men (Darrow 2017):

In the CDC cluster study, no assumptions were made about who infected whom… Some of the sexual partners of Patient 0 were healthy when initially contacted and subsequently developed AIDS, but CDC collected no evidence to prove that Patient 0 infected any of his sexual partners.

Ultimately, widespread excoriation of Shilts’ reporting on the 1984 cluster study doesn’t consider an historical lens: it would be decades until the etiology of HIV/AIDS was clear. In fact, as late as 2013, AIDS Vancouver was still reporting Dugas as the “first person diagnosed with AIDS in North America” (AIDS Vancouver 2013). Darrow points out in 2017 that efforts to trace the etiology in 1982 were primitive and not informed by what would become clear in the twenty-first century, and he clarifies how frustrated Shilts’ was over failure to apply precautionary principles to mitigate presumed sexual spread of HIV/AIDS. Darrow concludes with a powerful vindication of Shilts’ reporting on the cluster (Darrow 2017):

Unfortunately, when AIDS was being recognized in June 1981, as many as 300,000 people may have already been infected with the virus on at least three continents. Only a few were aware of the disease and its potential consequences….

Randy Shilts witnessed the exponential growth of the epidemic to over 50,000 AIDS cases reported in the United States by the time [he died in 1994]. He believed early on that a sexually transmitted agent was spreading rapidly among men who have sex with men (MSM) in San Francisco. He couldn’t understand why city health authorities failed to close the bathhouses where he knew so many new infections were contracted. Subsequent studies have proved him right. The estimated incidence of HIV infection among MSM in the United States rose rapidly, from fewer than 100 men infected per year in 1977–1979, to 12,000 per year in 1980–1981, to 44,000 per year in 1982–1983, to 74,000 per year in 1984–1985. Sharp declines in HIV incidence followed as America finally began to respond to AIDS, but the irreversible damage of institutional failure and national neglect had been done.

**From GRID to AIDS: Blood, Sweat and Tears**

In covering the early days of the AIDS epidemic, it’s important to make clear that the first label assigned to the disease by the medical community itself was “Gay-Related Immune Deficiency” (GRID). In fact, at UCLA, when Gottlieb first began to see gay males with the disease, the first patient that died from pneumocystic carinii pneumonia (PCP) commented to his health team: “I guess I am one sick queen” (Hillman 2017). Thereafter, UCLA initially dubbed the new epidemic “SQUIIDS”—for “Sick Queen Immune Deficiency Syndrome” until the term was banished from use (Hillman 2017), and the term “GRID”—Gay-Related Immune Deficiency—took hold. In the first published papers in MMWR (CDC 1981a, b) and the New England Journal of Medicine (Gottlieb et al. 1981), a causal association of “homosexual” and immune deficiency was made, reinforced by the New York Times article that mentioned the term GRID as well as “A.I.D.” The terminology change to Acquired Immune Deficiency Syndrome, or “AIDS” was depicted in the film, And the Band Played On,
which dramatized a July 27, 1982 meeting of stakeholders, comprising hemophiliac organizations, blood industry officials, members of the gay activist/political community, representatives from the CDC, NIH and the FDA. At this point, it was clear that the disease was not “gay related” but a virus transmitted through sexual contact as well as blood, because intravenous (IV) drug users and hemophiliacs were becoming infected as well. Additionally, Haitians of both sexes were becoming infected due to a cluster there traced to 1979. Between 1979 and 1982, 61 cases of AIDS were diagnosed in Haiti, where the infection initially spread in an urban area with high rates of prostitution, and there were questions as to whether Haiti brought HIV to the United States or was it the reverse (Koenig et al. 2010; Farmer 2006).

The historical July 1982 meeting wound up being very contentious with many groups opposed to implementing any guidelines for protecting the blood supply fearing social harms to certain groups through stigma. The CDC suggested that people in high-risk groups ought to refrain from donating blood: gay men, IV drug users and Haitians were considered “high risk” donors. The meeting was described this way (Nussbaum 1990):

The meeting was a disaster. Hemophiliac groups didn’t want their blood disorder to be associated with a gay disease. Gay community leaders were fearful that being prevented from donating blood was just the first step in quarantining all gay men. Indeed, right-wingers in Washington were already making noises about sending gays to “camps.” The FDA and the CDC fought over turf. Regulation of the blood industry fell under traditional FDA authority. The involvement of the CDC was perceived as a threat. Many FDA doctors didn’t even believe that a new disease existed. They thought the CDC was simply stitching together a number of unrelated diseases to boost their budget funding.

No one was willing to agree to anything except to wait and see. There was one accomplishment, however. Different groups on different coasts were calling the new disease by many different names. Gay-Related Immune Deficiency was the most popular, but it was clearly untrue since IV drug users and Haitians were shown to be vulnerable. Gay cancer was used mostly in New York, but it focused on only one of the many opportunistic infections associated with the disease.

Someone at the meeting suggested AIDS - Acquired Immune Deficiency Syndrome. It sounded good. It distinguished this disease from inherited or chemically induced immune deficiencies. It didn’t mention the word gay or even suggest gender. AIDS. It stuck.

July 27, 1982, the day the CDC adopted AIDS as the official name of the new disease, is the official date of the beginning of the AIDS epidemic. At that point, about five hundred cases of AIDS had already been reported to the CDC, of whom approximately two hundred had died. Cases had been diagnosed in twenty-four states, and the pace of new diagnoses was doubling every month. The CDC started calling the outbreak an epidemic.

Notes Shilts (1987:171):

Somebody finally suggested the name that stuck: Acquired Immune Deficiency Syndrome. That gave the epidemic a snappy acronym, AIDS, and was sexually neutral. The word “acquired” separated the immune deficiency syndrome from congenital defects or chemically induced immune problems, indicating the syndrome was acquired from somewhere even though nobody knew from where.
Ultimately, the one notable good outcome of the meeting was the adoption of *Acquired* Immune Deficiency Syndrome (AIDS) as the formal label of the new epidemic. The one notable terrible outcome, however, was the refusal by decision-makers to take early steps to protect the blood supply. Although screening the blood supply could not occur prior to the discovery of HIV and an HIV test (see further), donor screening using questionnaires and data about high risk groups could have had a significant impact, and would have saved likely thousands of lives. At this meeting, three cases of hemophiliac deaths from PCP led to the conclusion that the virus was indeed in the public blood supply (IOM 1995), hence the line “how many dead hemophiliacs do you need?” It’s worth noting that many students do not have a background or understanding of the disease, hemophilia, which is an X-linked disease afflicting mostly male children. It afflicted Richard Burton, who was married to Elizabeth Taylor (see earlier), as well as Roger Ailes, former CEO of Fox News, who died from it in 2017 after a fall. In covering the history of AIDS, a primer on hemophilia, the invention of clotting factor and Factor VIII is important, but I will not address it here. If hemophiliac infections via Factor VIII wasn’t convincing enough, there was certainly strong evidence by early 1983 that AIDS was a blood borne virus that could be transmitted through blood transfusion, due to hundreds of transfusion-AIDS cases by then, including pediatric AIDS cases from maternal blood transfusions during childbirth. For example, Elizabeth Glaser (wife of actor Paul Michael Glaser) contracted AIDS as early as 1981, from a blood transfusion during childbirth, and passed it to her daughter through breastfeeding. Her second child then contracted the virus in utero. This became the story of thousands of women and children. By 1984, 12,000 cases of transfusion-HIV infections had occurred (IOM 1995). Yet despite the evidence that AIDS could be transmitted through transfusion, the blood industry declined to accept the CDC recommendations to implement any screening strategies (see under Healthcare Ethics Issues).

Astonishingly, between 1982 and 1985, absolutely no attempt to screen or protect the public blood supply was made. Even after the HIV virus was identified (see further), widespread screening of the blood supply did not occur until 1985, when the ELISA (and later Western Blot) tests were finally developed (see further). Even after 1985, untested blood continued to be used even after the ELISA testing was developed. The Institute of Medicine (IOM) concluded: “Inappropriate incentives inhibited reasonable decision-making by the responsible parties” (IOM 1995).

Some of the “inappropriate incentives” had to do with perception problems of the populations affected. Ultimately, although the transition from GRID to AIDS occurred early in the epidemic, the connotation that the disease was “gay related” would remain for at least 15 years, and likely affected delays with protecting the public blood supply. Ironically, although Rock Hudson’s AIDS death was automatically associated with his being a homosexual and the presumption he got the virus through sex, it is also likely he got AIDS through a transfusion while undergoing heart surgery in 1982 (People 1982).
Discovery of the Virus that Causes AIDS: LAV, HTLV III and HIV

Not since the discovery of insulin in 1921, in which two research teams bitterly fought for the credit and shared recognition for the Nobel Prize (Bliss 1982) has there been such an ugly and public fight for credit as the discovery of the virus that causes AIDS. The book and the film, *And the Band Played On*, covers the Robert Gallo story and paints him as a highly problematic figure in the early years of AIDS. In fact, the film, more than the book, functions as a vehicle for Gallo’s public shaming.

In a translational research race to discover the virus, researchers at the Pasteur Institute are the first to succeed in 1983, and published their discovery on May 20, 1983, in *Science* (vol. 220, p. 868). Dr. Luc Montagnier’s research group found a new virus that causes AIDS, which they name lymphadenopathy virus (LAV). As the first article on a new virus, the paper made clear that more confirmatory research was required. A Scottish Inquiry that looked at this period in science history summarized it this way (Penrose 2015):

> The tentative conclusion of the article was that the virus belonged to a family of T-lymphotropic retroviruses that were horizontally transmitted in humans and might be involved in several pathological syndromes, including AIDS. The conclusion was uncommitted on the issue of whether the new virus was the etiological agent causing AIDS... The full significance of the French discovery was not widely acknowledged in 1983....

Despite the hesitancy expressed by Montagnier, there was growing interest in the scientific community in the hypothesis that transmission of a virus caused AIDS, and for some specialists the Montagnier discovery was significant. After the publication of their paper in *Science*, however, the French scientists struggled to persuade some others in the field that the virus they had isolated was indeed the cause of AIDS....

When the retrovirus “King” Dr. Robert Gallo, a renowned researcher at the National Cancer Institute, learns of the news he clearly understood the significance, but plays down his French colleagues’ discovery. As depicted in the public record, Shilts’ book and the film, he “gaslights”, suggesting LAV is merely a variation or relative of a retrovirus that he discovered years earlier, and part of the HTLV family of viruses linked to feline leukemia that he is working on. In April 1984 Gallo reports that his team has now found the definitive virus that causes AIDS, which he names the human T cell lymphotropic virus type III (HTLV-III)\(^3\); he publishes his finding on May 4, 1984 in *Science* (vol. 224, p. 500).

> On April 23, 1984: “[Health and Human Services] Secretary Margaret Heckler announced that Dr. Robert Gallo of NCI had found the cause of AIDS, the retrovirus HTLV-III. She also announced the development of a diagnostic blood test to identify HTLV-III and expressed hope that a vaccine against AIDS could be produced within two years” (NIH 2019). According to the Scottish Inquiry (Penrose 2015):

> The tide only turned in France when Robert Gallo and his group in the United States made a similar discovery. In the spring of 1984, Gallo published more convincing evidence …It

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\(^3\)Also reported as HTLV-IIIB, standing for human T-cell leukaemia/lymphoma virus type IIIB.
was announced that a retrovirus belonging to the HTLV family and designated HTLV-III had been isolated from a total of 48 subjects, some with AIDS, some with ‘pre-AIDS’ and some without symptoms but in risk groups. The authors concluded that HTLV-III might be the primary cause of AIDS.

Gallo’s announcement was a turning point in developing knowledge worldwide. The evidence that people who had AIDS-like symptoms had antibodies against HTLV-III was more compelling circumstantial evidence that the virus was associated with the disease than finding the virus itself in somebody with the illness…Gallo’s work was a major contribution to developing knowledge…However, the impression given overall is that, leaving aside all national prejudices, internationally there was cautious scepticism among many opinion leaders about the French research, until Gallo’s announcement. The Montagnier/Barré-Sinoussi team did not have a long track record of discovering viruses. Their work did not have the international esteem required to spark the scientific research and development that followed the work of the Gallo group.

Montagnier stated in 2002 (Penrose 2015):

Our [1983 results] were still controversial … and we had difficulty in obtaining the funding needed to better characterize the virus and develop a blood test.

In June 1984, Drs. Robert Gallo and Luc Montagnier held a joint press conference to announce that Gallo’s HTLV-III virus and Montagnier’s LAV were virtually identical, which suggested foul play on Gallo’s part, which is detailed in the film, exposing Gallo as potentially appropriating or manipulating Pasteur Institute materials he was sent for verification.

This led to delays in more robust translational research because there were disputes over whether LAV, HTLV-III or both, were the viruses that cause AIDS, which would also affect patents. Nonetheless, the NIH developed a test under Gallo’s patent in 1985 that could detect exposure to so-called HTLV-III, while in France, an LAV test is also developed as well as experimental treatments for AIDS (see further). But in a “VCR versus Betamax” situation, the HTLV III test establishes itself as the mainstream lab test.

In 1985, the Pasteur Institute filed a lawsuit against the National Cancer Institute because the test for HTLV III was also a test detecting LAV, which they discovered, and was an identical virus. They wanted a share in the royalties from the HTLV-III test. Thus, early testing and treatment for AIDS was confusing; clinicians on the ground began referring to “LAV/HTLV-III” as the virus that causes AIDS, basically acknowledging they were the same virus found by different teams. While the United States took the lead in testing, raking in millions of dollars in profits from the test, the French took the lead in experimental treatments. Between 1984-1987, AIDS patients, including Rock Hudson, would go to Paris for experimental treatments with HPA-23 (see further).

As the LAV versus HTLV-III dispute persisted, the Pasteur Institute’s lawsuit threatened to expose major scientific misconduct by Gallo, prompting an international committee of scientists in 1986 to intervene (Marx 1986). Called the “Varmus Committee”, it was led by Dr. Harold Varmus, Chair of the Retrovirus Study Group within the Vertebrate Virus Sub-committee of the International Committee
on Taxonomy of Viruses. The committee, which included Montagnier and Gallo, proposed new virus nomenclature, and that the virus be renamed to Human Immunodeficiency Virus (HIV). At the time, not only was there the “LAV” v. “HTLV-III” name recognition problem, but another AIDS researcher, Jay Levy, from the University of California San Francisco, had also isolated the AIDS virus in 1983 but didn’t publish; he called it AIDS-Associated Retrovirus (ARV). Politically, whichever name was formally recognized would be associated with who was credited for the discovery. So, in May 1986, agreement was reached by all but two committee members (Gallo and Max Essex) to rename the virus HIV, and the test would become known thereafter as the “HIV antibody test” (aka HIV test). Despite this arrangement, the French pursued their lawsuit.

A memo from Don Francis at the CDC about what the lawsuit would uncover reads (Shilts 1987):

If this litigation gets into open court, all the less-than-admirable aspects will become public and, I think, hurt science and the [U.S.] Public Health Service. The French clearly found the cause of AIDS first and Dr. Gallo clearly tried to upstage them one year later.

Don Francis is writing this memo as the Public Health Service is still licking its wounds from the Tuskegee study a decade before, which is now freshly in the news due to James Jones’ book, Bad Blood, published in the early 1980s (see Chap. 1). Shilts further notes (Shilts 1987):

On the most central issue of whether HTLV III was the product of viral pilfering Francis posed the hypothetical question: Could the prototype isolates of HTLV-III and LAV be identical merely by coincidence? And he answered “Probably not.”

By 1987, Jonas Salk, who discovered the polio vaccine, became the mediator in the dispute with shuttle diplomacy, getting both parties to agree to be considered co-discoverers of HIV. The Pasteur Institute also demanded that the United States “turn over its half of the profits from the blood test—about $50 million since 1985” (Hilts 1992). In the end, the debacle became an international incident in which both the U.S. and French Presidents signed an agreement in 1987 between the two countries to share credit. As reported by the Washington Post, “the dispute over Dr. Gallo’s claims became so linked to national scientific prestige that the Presidents of France and the United States attempted to end the conflict in 1987 when they agreed to a 50–50 split of credit and patent royalties from work with the AIDS virus and the blood test to detect it (Gladwell 1992).

1989: The Chicago Tribune Story and Federal Investigations

In 1989, an explosive 50,000-word investigative report by John Crewdson of the Chicago Tribune (Crewdson 1989), reviewed the Gallo matter again, and concluded that he had engaged in frank misconduct. The Chicago Tribune story led to a formal federal investigation—comparable to a science version of the “Mueller Report”—into Gallo’s laboratory to see if he was indeed guilty of research misconduct. A 1991
summary of the report found Gallo and his laboratory guilty of scientific misbehavior and unprofessionalism but not overt misconduct. By 1992, a re-analysis by an independent panel concluded that Gallo indeed committed misconduct, and that he had “falsely reported” a key finding in his 1984 *Science* paper regarding isolating the AIDS virus (Michaelson 1993; Hilts 1992). According to the *New York Times* (Hilts 1992):

> The new report said Dr. Gallo had intentionally misled colleagues to gain credit for himself and diminish credit due his French competitors. The report also said that his false statement had “impeded potential AIDS research progress” by diverting scientists from potentially fruitful work with the French researchers.

Most of his critics argued that Dr. Gallo had tried to take credit for work that French scientists had done and that he may even have taken the virus the French were studying and claimed it as his own. At the time, the virus was difficult to isolate and grow in sufficient quantity for research. In addition, the report found that Dr. Gallo warranted censure on …four other counts [including his] referring to his role as a referee for a different article submitted to a journal by his French competitors, in which he altered several lines to favor his own hypothesis about the AIDS virus [for reasons that were] “gratuitous, self-serving and improper.”

The focus on Gallo in the film reflects the findings from both the *Chicago Tribune* article and the 1992 report. While the film was in production, Gallo’s attorneys threatened HBO with a lawsuit (Cooper 2019), but HBO felt it was on solid legal ground. As the film was in production, the *New York Times* published a useful mini-history of the entire LAV-HTLV controversy for its readers, which included a chronology of events that took place over the same time line as Shilts’ book and the film. Here it is (Hilts 1992b):

**Chronology: “Years of Scientific Dispute”**

1983: French scientists under Luc Montagnier at Pasteur Institute report discovery of a virus that might be the cause of AIDS.

1984: Ignoring French claim, U.S. scientists at National Institute of Health under Dr. Robert C. Gallo announce discovery of such a virus and proof that it causes AIDS.

1985: A blood test for antibodies to the AIDS virus is licensed. The French sue the U.S. Government over credit for the discovery of the virus.

1987: President Ronald Reagan and Prime Minister Jacques Chirac announce an agreement on sharing credit and divide royalties for the blood test.

1989: A Chicago Tribune article suggests that Dr. Gallo improperly took credit for the Montagnier discovery.

MARCH 1990: A [Chicago Tribune] report asserts that Dr. Gallo’s virus was probably identical to the Pasteur Institute virus.

OCTOBER 1990: The National Institutes of Health says it will open a full-scale investigation of the matter by the Office of Scientific Integrity because a preliminary investigation suggested the possibility of misconduct.

MAY 1991: Dr. Gallo formally concedes that the viral cultures were probably contaminated by French samples but maintains that he is a co-discoverer.
SEPTEMBER 1991: Preliminary report by Office of Scientific Integrity finds evidence of misconduct by Dr. Gallo. Final report holds that he is not guilty of misconduct but deserves censure for permitting lapses and misrepresentations by those under him.

MARCH 1992: New investigation of charges of perjury and patent fraud announced by Inspector General of Department of Health and Human Services, the General Accounting Office and a House subcommittee.

DEC. 30, 1992: Report of Office of Research Integrity of Department of Health and Human Services says Dr. Gallo grew Dr. Montagnier’s virus in his own laboratory and misled colleagues to gain credit for himself. (pg. A20)

A Washington Post review of the controversy in Spring 1992 fleshed it out this way (Gladwell 1992):

The Gallo controversy dates from 1982, when two laboratories – Gallo’s at the National Cancer Institute and a French research team headed by Pasteur Institute researcher Luc Montagnier – began working simultaneously to track down the cause of the then-mysterious disease that was striking homosexual men.

First to publish was Montagnier, who described finding a virus, which he dubbed LAV, in an AIDS patient in May 1983. Montagnier, however, stopped short of claiming it was the cause of AIDS. In April 1984, Gallo went further. He announced that he too had identified a virus, and proposed that it was the cause of AIDS. Gallo also reported having developed a test to detect the virus in blood…. When Gallo’s AIDS virus and Montagnier’s AIDS virus were compared, they turned out to be the same. And because Montagnier had sent Gallo a sample of the French lab’s virus early in the research process…Did Gallo steal the French virus and claim it as his own? Or did accidental contamination occur, as is common in laboratories working with highly infectious viruses like HIV?

The French, assuming the former, sued. That suit was settled in 1987 when the two parties agreed to share credit equally for having discovered the AIDS virus. There the matter rested until November 1989, when Chicago Tribune investigative reporter John Crewdson published a 50,000-word article implying that Gallo had deliberately stolen the virus and alleging a broader pattern of unethical behavior on Gallo’s part.

The article prompted the NIH inquiry, which began in late 1989. The review entailed painstaking reconstruction of events of the period in question through numerous interviews and analysis of thousands of pages of documents.

By December 1992, a scathing conclusion was reached over Gallo’s putative “explanation” for his 1984 Science paper’s report that his lab had found the virus for AIDS (Crewdson 1992). In that same paper (Popovic et al. 1984), he essentially stated that LAV would not grow in his lab, so it couldn’t possibly be labelled as the virus responsible for AIDS. Then, he backtracked in 1991, stating that his 1984 findings were accurate at the time, and he only recently deduced that his cultures must have become cross-contaminated with the Pasteur Institute’s culture. The Office of Research Integrity didn’t buy it (Hilts 1992):

[The Office of Research Integrity’s] new report said, “Dr. Gallo falsely reported the status of L.A.V. research …and this constitutes scientific misconduct…The explanations that Dr.
Gallo proffered for the statement are neither credible when the evidence is considered, nor do they vitiate the impropriety of falsely reporting the status of L.A.V. research.

In the end, Gallo is credited as a co-discoverer of HIV, but the treatment of the Gallo content in the 1993 film, *And the Band Played On*, forever branded his reputation and career. He left the NIH tarnished, and went to the University of Maryland, continuing to earn a profit from the HIV test of roughly $100,000.00 a year in royalties. In reality, Gallo’s conduct stymied meaningful translational research into AIDS treatments. But Gallo continues to deny any wrongdoing, and now blames the entire controversy on cell line cross-contamination. Crewdson penned a book in 2002 about Gallo (Crewdson 2002; Horgan 2002) reviewing the entire controversy.

The Nobel Prize for HIV

In 2003, 20 years after of the discovery of HIV, Gallo and Montagnier published a joint retrospective on the discovery of HIV (Gallo and Montagnier 2003), in which they first give due credit to Gallo for having done the basic science work in retroviruses to begin with, which led multiple teams to search for such a virus as the cause of AIDS. The paper also implied that Gallo inadvertently mistook Montagnier’s isolate for his own due to cell line contamination. Essentially, Gallo admits that he inadvertently “rediscovered” what Montagnier had first discovered from the exact same cell line. It is unknown if the 2003 paper by the “co-discoverers” of HIV was invited as a truce by the editor of the *New England Journal of Medicine*. But clearly it did not influence anyone on the Nobel committee.

By 2008, 25 years after the Pasteur Institute discovered LAV, the Nobel Prize in medicine was awarded to Luc Montagnier and Françoise Barré-Sinoussi for discovering the HIV virus in 1983; Robert Gallo was excluded. The rationale was straightforward: Montagnier’s group was the first to publish in 1983. Through the years, it became clear that his group was indeed the first to discover the AIDS virus. By 1990, the seminal HIV discovery paper that was cited was Montagnier’s *Science* paper (Barre-Sinoussi et al. 1983) and not Gallo’s. Meanwhile, what Gallo published a year later in 1984 (Popovic et al. 1984) turned out to be from Montagnier’s sample, but he renamed the virus and quickly filed a patent for a test that earned millions. Years of gaslighting, denial and finally, admission that it was all a terrible misunderstanding due to cell line contamination, left Gallo’s reputation in tatters, with an explanation that was …well, prizeless.

To date, *And the Band Played On* remains the only film that documents one of the most notorious battles for credit in science history. But the Nobel decision also validates the role investigative journalism played (Miner 2008):

This [Nobel Prize decision] might be interpreted as the ultimate vindication of reporter John Crewdson, who in 1989, in a 50,000-word story in the Chicago Tribune, argued that Gallo – credited back then with codiscovering the virus – had merely rediscovered Montagnier’s virus, which had been sent to Gallo as a professional courtesy.
The HIV Test and Early Experimental Protocols

As discussed above, the first HIV test was patented by Gallo in 1985, and was an antibody assay designed to detect HTLV-III, and was manufactured by the pharmaceutical companies, Abbot and Electronucleonics, using HTLV-III isolates. At the same time, the Pasteur Institute had also developed a similar test to detect LAV, which was manufactured by the biotech company, Genetic Systems, using LAV isolates (Penrose 2015). The HTLV-III test is what was predominantly used. The first HTLV-III test was not designed to “diagnose AIDS” but to look for exposure to the virus that causes AIDS. The blood test was really designed as a tool to prevent transmission of the blood borne virus and to screen potential blood donors or banked blood. Ultimately, the first generation test became widely known in the medical literature as the “Anti-HTLV III/LAV assays” (Mortimer et al. 1985), but generally referred to the Gallo-patented test. The issue with the early tests is that they were unable to detect antigens, only antibodies. Despite the availability of all kinds of blood donor screening strategies (see under Healthcare Ethics Issues), it was not until the development of the first generation test in 1985, when widespread screening of the blood supply began. But untested blood continued to be used even after the test was developed. FDA approved the first enzyme linked immunosorbant assay (ELISA) test kit to screen for antibodies to HIV.

False Positives and Negatives

The following 1986 Letter to the Editor characterized early concerns with the HTLV-III test (Yomtovian 1986):

During the last several months, much attention has been directed to the number of false-positive results of the test for the [HTLV-III] antibody. Concern has focused primarily on use of this test to screen blood donors and the worry that a large number of healthy donors would be falsely branded as HTLV-III viral carriers. While this is an important and valid concern, some of this worry has already been dispelled. What remains largely unaddressed, however, is the number of false-negative results of the HTLV-III antibody test. There are now published case reports of individuals who are HTLV-III viral culture positive, but HTLV-III antibody negative.

With the first generation of tests, testing negative was only reassuring if the test was done at least 12 weeks after potential exposure. The high sensitivity of the first antibody tests were designed primarily for protecting the blood supply, which was still slow-walked. But in many ultimately HIV-negative individuals, false-positive results were associated with other conditions such as infections, autoimmune disease or pregnancy (Alexander 2016). The testing was recommended for anyone who had unprotected sex since 1977, or had a blood transfusion since 1978, but this included many groups of low-risk individuals. Confirmatory testing was added for accuracy, which included the Western blot assay (Alexander 2016). By April 29, 1987, around the time Shilts’ book is published, the FDA approved the first Western blot blood test
kit—a more specific test, which began to be routine for certain hospital procedures (Banks and McFadden 1987). These second-generation tests could detect the virus within 4-6 weeks of exposure, and was the testing in place when the film came out in 1993.

By the late 1990s, HIV tests that combined antibody and antigen detection were developed, and could detect the virus within 2 weeks of exposure; this test gave one result but didn’t distinguish whether the result was due to HIV antibodies or HIV antigens.

From a history of medicine standpoint, testing in the pre-treatment period was mainly for the benefit of third parties so that HIV-positive people could practice safe sex and other precautions; and that donor screening could prevent transfusion-AIDS. But pre-treatment testing also meant that testing positive could lead to enrollment in clinical trials (see further), which were few and far between. Frequently testing positive led to a social death where friends and employers abandoned the HIV-positive person, while depression and anxiety that came with any terminal illness diagnosis—even for those who were asymptomatic. A positive test did not predict when AIDS would materialize, given the high variability from HIV exposure to full blown AIDS. Testing positive for HIV prior to treatment raised very similar issues as genetic testing for diseases such as Huntington’s disease.

The implication of HIV testing in the treatment era changed everything, as prophylactic therapy could be administered as soon as possible.

Ultimately, the main issues with HIV testing were the ethical issues: mandatory testing versus voluntary testing; access, privacy, insurance, and the duty to warn, which are all discussed further (see under Healthcare Ethics Issues). Many of these issues led to legal protections for HIV-positive patients, such as HIPAA, but access to treatment and insurance remained a problem even when treatment was available.

For current healthcare trainees, rapid HIV tests after exposure is the norm, while home HIV tests are now available on drugstore shelves (FDA 2018). For these reasons, it’s important to emphasize the social stigma that was associated with earlier generations of testing, and the absence of legal protections, employment protections, healthcare access and social supports for those who tested positive.

Americans in Paris: HPA-23

HPA-23 was the first experimental antiretroviral used to treat HIV/AIDS patients; trials began in Paris in 1984, but were found to be ineffective. Montagnier and his team patented it, and began experimental trials almost as soon as HTLV-III/LAV were established as the AIDS virus. Preliminary research suggested that it slowed the progression of the virus. Because France had more permissive guidelines for experimental treatments, it went ahead with the HPA-23 trials in the absence of any other treatment or therapy.

The French team welcomed American patients as medical tourists to their HPA-23 trials, and treated over 100 Americans during this timeframe, which included Rock Hudson (see earlier), and San Francisco politician, Bill Kraus, featured as a major
character in the film, *And the Band Played On*. American clinicians cautioned about pinning too much hope on HPA-23 (Raeburn 1985). Anthony Fauci noted at the time: “There really is no indication at all that [HPA 23] is any better, and it’s considerably more toxic...HPA 23 causes a drop in the levels of blood cells called platelets, which in turn can lead to bleeding disorders” (Raeburn 1985). Eventually, the FDA succumbed to pressure from AIDS patient advocates to allow limited clinical trials in 1985. By 1986, it became clear that there was no therapeutic future with HPA-23, as the side-effects of the drug proved more problematic without any significant potential benefit (Moskovitz 1988).

**From AZT to Cocktails**

After the failed trials of HPA-23, a promising anti-retroviral therapy materialized with the drug, AZT (azidothymidine), a reverse-transcriptase inhibitor, also known by the name, Zidovudine. This drug was first discovered in 1964 as part of an NIH grant; it was investigated as a potential anticancer drug. It was found to inhibit the growth of the Friend leukemia virus in cell culture by inserting itself into the DNA of a cancer cell and interfering with its ability to replicate. It was abandoned when it didn’t work well in mice and practical application seemed limited. After the Pasteur Institute discovered LA V in 1983 (see earlier), researchers at the NCI actively began a program to look for any drug or compound that had antiviral activity, and dug up the research results on the compound that became AZT, in addition to 11 other compounds that had potential. When tests were done in vitro, it blocked the HIV virus’ activity.

By early 1985, Burroughs-Wellcome patented AZT, and a phase I clinical trial with started at Duke University. The results of that first trial demonstrated that AZT was safe and well-tolerated; increased CD4 counts and restored T cell immunity, and that AIDS patients were recovering on it. Then a large multi-center double-blinded randomized controlled trial with 300 patients began, which was halted after 16 weeks when it was clear that patients on the drug were getting better. In the placebo group, 19 patients had died, while the AZT group lost only one patient. Stopping the trial early was ethically defensible because the benefits clearly outweighed the risks of the placebo in the absence of any other treatment available for AIDS patients (Fischl et al. 1987).

AZT was approved by the FDA March 19, 1987, as an accelerated approval for both HIV-positive patients and AIDS patients, who had “AIDS-related Complex”—an antiquated term that just meant clinical symptoms of opportunistic infections. From the first clinical trial until FDA approval, 20 months had passed, but it had been, to date, the shortest approval process in the FDA’s history at that time; in 1987, new drugs investigations took 8–10 years before they were approved.

One AIDS practitioner recalled (Sonnabend 2011b):
I’m not sure that it’s even possible to adequately describe the terror and desperation felt in the early 1980s. By 1986 nothing of any use regarding treatments had come from the Public Health Service and very little from the academic medical community.

Then, after six years of inaction we were at last told that help was on the way. Dr. Samuel Broder who was head of the National Cancer Institute appeared on television shows trumpeting the benefits of a drug he called Compound S [later patented as AZT]. I well remember a TV show where he appeared with a person with AIDS who enthusiastically attested to the benefit he had received from the drug, presumably from 1.5G of it daily.

The clinical trial on which AZT’s approval was based had produced a dramatic result. Before the planned 24 week duration of the study, after a mean period of participation of about 120 days, nineteen participants receiving placebo had died while there was only a single death among those receiving AZT. This appeared to be a momentous breakthrough and accordingly there was no restraint at all in reporting the result; prominent researchers triumphantly proclaimed the drug to be “a ray of hope” and “a light at the end of the tunnel”. Because of this dramatic effect, the placebo arm of the study was discontinued and all participants offered 1500 mg of AZT daily.

But some clinicians were critical of AZT’s early approval because (Sonnabend 2011a, b):

It took place in 12 centers across the country. There was no uniform approach to patient management during the trial; each of the 12 medical centers determined this independently. So the most important series of measures determining life or death in the short term was left unspecified. I suppose one has to conclude that government medical experts, unlike community doctors, must have felt that nothing could be done for people with AIDS, that the only hope to be found was in a new drug.

AZT’s approval coincided with the publication of Shilts’ book; Shilts himself was on AZT until he died in 1994. AZT slowed the replication of the HIV virus, which prevented or delayed the progression of AIDS. Many HIV-positive patients were able to stave off full-blown AIDS for years on AZT until the protease inhibitor era arrived a decade later, in which AZT became part of a “cocktail” of drugs that typically included a second reverse-transcriptase inhibitor and an antiretroviral drug from another class of drugs (see further).

In June 1989, the first set of prevention guidelines for AIDS-related diseases and prevention of HIV transmission were published by the CDC, while the NIH endorsed access to experimental therapies for AIDS patients. Meanwhile, federal funding for hospice care was made available to community-based care programs in many states. While AZT was a breakthrough, it was not necessarily a sea-change as many patients either couldn’t access it, or became resistant to it.

AZT Side-Effects, Efficacy, and Cost

AZT was initially prescribed at high doses (1500 mg), and had severe and sometimes toxic side-effects of anemia and malaise and liver damage. According to one critic of the initial dosing regimen (Sonnabend 2011a, b):
...[T]he drug was still approved at a dosage that proved to be so toxic that another trial compared a similar dose with half that dose. This exercise resulted in excess deaths among those taking the higher dose.

Indeed, a “randomized controlled trial of a reduced daily dose of zidovudine in patients with the Acquired Immunodeficiency Syndrome” (Fischl et al. 1990) established that the initial dosing was too toxic, which also helped AZT gain approval in 1990 for pediatric patients.

But the biggest problem with AZT is that it stopped working after a time: the virus eventually mutated and became AZT-resistant. The second biggest problem was access and cost; at the time it was approved, AZT was considered the most expensive drug in history. *Time* magazine described it this way on the 30th anniversary of AZT (Park 2017):

> But even after AZT’s approval, activists and public health officials raised concerns about the price of the drug. At about $8,000 a year (more than $17,000 in today’s dollars) — it was prohibitive to many uninsured patients and AIDS advocates accused Burroughs Wellcome of exploiting an already vulnerable patient population.

As discussed earlier in this chapter, the cost of AZT led to the passage of the *Ryan White CARE Act* (Comprehensive AIDS Resources Emergency) in 1990, which took effect in 1991, and was designed to help vulnerable patients access HIV/AIDS treatments. Since then, millions of HIV/AIDS patients have used this law to get access to treatment, including protease inhibitors (see further). Today, AZT is listed as an Essential Medicine by the World Health Organization (WHO), and when the patent expired on AZT in 2005, generic versions of the drug were FDA approved, and the typical cost is now $2400 annually for U.S. patients, and between $5–25 per month for patients in poorer countries.

**The AIDS Cocktail: Protease Inhibitors**

As drug resistance became a major side-effect of AZT, it was clear that a multi-drug arsenal, known as the “cocktail therapy” would be the next generation of HIV/AIDS treatment. An AIDS research team led by David Ho at Rockefeller University Hospital, noted that “within the body of a single infected person, many different mutated versions of the virus exist” so it quickly evolves and becomes resistant with a single drug, such as AZT. According to Rockefeller University, Ho’s colleagues found (Rockefeller University 2010):

> [B]y giving patients three or four drugs at a time, [HIV] could not mutate rapidly enough to evade all of them. By 1996 they had succeeded in reducing [HIV] levels to the point of being undetectable in a group of patients treated with the new therapy. They discovered that treating patients with a combination of three or more antiretroviral drugs could keep the virus in check. The initial clinical trials of this therapy were carried out with patients at the Rockefeller Hospital. Today, in the developed world, AIDS is a manageable chronic disease thanks to the “AIDS cocktail” of combination antiretroviral therapy.
Ho began to publish his results on a class of drugs known as protease inhibitors, and by 1996, a protease inhibitor cocktail became the standard of care; 1996 was the year everything changed for HIV/AIDS patients.

Early drug research into the HIV protease led to specific protease inhibitors, now a component of anti-retroviral therapies for HIV/AIDS. When the HIV virus’ genome became known, research into selective inhibitors and selective antagonists against the HIV protease began in 1987, and phase I trials of the first protease inhibitor, saquinavir, began in 1989. The results were published in 1995 (James 1995) and, and about four months later, two other protease inhibitors, ritonavir and indinavir, were approved.

In its December 30, 1996 issue, when the burden of HIV infection was now greatest in African Americans, *Time* magazine named David Ho, discoverer of the AIDS cocktail therapy, as its “Man of the Year”, with several featured articles on Ho and AIDS. (In the same issue, there was an article on O. J. Simpson’s post-acquittal life.). The main AIDS article by Philip Elmer-Dewitt called “Turning the Tide” started like this: (Elmer-Dewitt 1996)

Some ages are defined by their epidemics. In 1347 rats and fleas stirred up by Tatar traders cutting caravan routes through Central Asia brought bubonic plague to Sicily. In the space of four years, the Black Death killed up to 30 million people. In 1520, Cortes’ army carried smallpox to Mexico, wiping out half the native population. In 1918 a particularly virulent strain of flu swept through troops in the trenches of France. By the time it had worked its way through the civilian population, 21 million men, women and children around the world had perished…Today we live in the shadow of AIDS—the terrifyingly modern epidemic that travels by jet and zeros in on the body’s own disease-fighting immune system.”

CNN noted about the *Time* pick for Man of the Year on December 21 1996 (CNN 1996):

*Time magazine picked AIDS researcher Dr. David Ho, who has pioneered the use of drug “cocktails” to fight HIV, as its 1996 Man of the Year.

“Some people make headlines while others make history,” Time said.

By 1998, Stanford University began the “HIV Drug Resistance Database” which helped to track the resistance mutations to refine cocktail therapies (Stanford University). In 2014, when *Time* named Ebola researchers Persons of the Year, the magazine reflected on the last time it had named any medical researcher as “Person of the Year”, and it was Ho. *Time* recalled (Rothman 2014):

[In 1996] AIDS was a death sentence — but Ho, by successfully lowering the virus count in patients who received a combination of new and powerful drugs when they’d only just been infected, helped change the way the medical community looked at HIV and AIDS.

In 2017, 30 years after AZT had been discovered, and 21 years after David Ho pioneered the cocktail therapy, *Time* summarized treatment like this (Park 2017):

Today, if someone is diagnosed with HIV, he or she can choose among 41 drugs that can treat the disease. And there’s a good chance that with the right combination, given
at the right time, the drugs can keep HIV levels so low that the person never gets sick…-
Today, there are several classes of HIV drugs, each designed to block the virus at specific
points in its life cycle. Used in combination, they have the best chance of keeping HIV at bay,
lowering the virus’s ability to reproduce and infect, and ultimately, to cause death. These
so-called antiretroviral drugs have made it possible for people diagnosed with HIV to live
long and relatively healthy lives, as long they continue to take the medications…And for
most of these people, their therapy often still includes AZT.

Treatment with the “AIDS cocktail”, or protease inhibitors—now known as antiretroviral therapy (ARV), led to early prophylactic therapy. With rapid testing
(see above), and starting early ARV before any symptoms begin, HIV/AIDS is not
only treated like a chronic disease, but recent drug trials reveal that HIV-positive
persons with undetectable viral loads may not even be infectious anymore. Over the
years, efforts to improve compliance with ARV led to the “one pill fits all” modality,
in which combination therapy is delivered through one pill, which comprises several
antiretroviral drugs.

To deal with high-risk groups, a new treatment modality evolved, known as “Pre-
exposure prophylaxis” (PrEP), which is when, according to hiv.gov:

…people at very high risk for HIV take HIV medicines daily to lower their chances of getting
infected. Daily PrEP reduces the risk of getting HIV from sex by more than 90%. Among
people who inject drugs, it reduces the risk by more than 70%. PrEP involves a combination
of two anti-retroviral drugs, and is currently sold as Truvada®.

One of the “Truvada for PrEP” commercials shows representatives from high-risk
groups (e.g. young African Americans of both sexes and white males) announcing:
“I’m on the Pill”, explaining that Truvada will protect them from getting HIV while
having sex.

While an HIV vaccine remains elusive as of this writing, treatment has changed
everything—to the point where the history and social location of And the Band Played
On could even be forgotten if it is not taught. While writing this chapter, commercials
for the drug, Biktarvy, were running, which is an ARV cocktail in one pill, or as the ad
notes. “3 different medicines to help you get to undetectable”. The ad shows happy
HIV-positive people: young African Americans doing an array of activities, along
with a presumably married gay male couple back from gourmet food shopping. The
ad looks indistinguishable now from an allergy drug commercial. As the ad explains
to potential patients: nothing in their lives needs to change, they should “keep on
loving” themselves for who they are, and the drug, combined with others, would help
them get to “undetectable”. One wonders what Randy Shilts would say if he saw that
ad today (which actually aired while Pete Buttigeig was declared the winner of the
2020 Iowa Caucus).

**Healthcare Ethics Issues**

As mentioned at the start of this chapter, And the Band Played On is what I call a
“Maleficence blockbuster” because of the laundry list of ethical violations housed
under the Principle of Non-Maleficence, which obligates healthcare providers not to knowingly or intentionally cause harm, knowingly neglect, discriminate against, or abandon a patient, or knowingly withhold or not disclose information about material risks or harms, which are necessary for informed consent. As Shilts’ makes clear in his book, the chaotic early years of AIDS was “allowed to happen” through poor decision-making in every critical theater of healthcare from policy to bedside. For these reasons, it’s useful to cover the most egregious ethical violations shown in the film from the standpoint of each healthcare theater: The Bedside Theater, the Public Health Theater and the Research Theater. There are also a range of ethical violations in the HIV/AIDS story that are beyond the scope of the film, as the film ends before the testing and treatment era, which I will summarize briefly at the end of this section.

**The Bedside Theater: Clinical Ethics Violations**

The original sin that occurred at the bedside was provider discrimination against AIDS patients based upon their status as homosexuals. Next, labelling the newly recognized syndrome “gay-related immune deficiency” (GRID—see under Medical History) had unintentional consequences and became highly problematic once the syndrome was understood to be a blood-borne virus in 1982. Although the nomenclature was changed to AIDS in July 1982, the disease by then was inexorably linked to being “gay-related” forever after, no matter what it was called. The association of “gay” with “AIDS” seriously interfered with public policy, funding and resources that could have helped contain/manage the virus earlier on. For example, at UCLA, the idea of a major grant focused on AIDS was so undesirable to institutional stakeholders, the institution denied tenure to a faculty member with a multi-million dollar grant to start an AIDS treatment center to avoid the “stigma” of servicing so many AIDS patients (see under History of Medicine with respect to the Michael Gottlieb story). In other words, UCLA did not want to be a center of excellence in the early 1980s for gay males and IV drug users. In the pre-testing era, this level of discrimination against AIDS patients also made non-gay AIDS patients a target of much more discrimination from healthcare providers, their employers and social networks. In this timeframe, many healthcare providers, in fact, refused to treat, examine or care for AIDS patients, which led to the creation of multiple gay community-based caregiving programs, such as the Gay Men’s Health Crisis (GMHC) in New York City, and similar programs elsewhere. Although healthcare provider discrimination is a theme that is far more expansive in the *Normal Heart* (2014), *And the Band Played On* features scenes in which the “buddy system” is discussed—where laypeople in the gay community took up the caregiving burden in the absence of healthcare providers willing to treat, which frequently included caregiving for in-patients at hospitals when healthcare providers refused to enter the rooms. In fact, the rise of articles on Professionalism and Humanism in medicine (see Chap. 8) coincided with the AIDS crisis.
Moral Distress and 1112 and Counting

As discussed earlier in this chapter, the first clinical ethics treatise on the AIDS crisis was written by Larry Kramer with a powerful “moral distress” piece that laid bare the discrimination and abandonment at the bedside, as well as the failure of adequate resources to deal with the epidemic. It is also a clarion call for safe sex in his community in the context of gay liberation, closeted homosexuals, and promiscuity (For the entire article see link at the reference, Kramer 1983⁴):

There are now 1,112 cases of serious Acquired Immune Deficiency Syndrome. When we first became worried, there were only 41. In only twenty-eight days, from January 13th to February 9th [1983], there were 164 new cases - and 73 more dead. The total death tally is now 418. Twenty percent of all cases were registered this January alone. There have been 195 dead in New York City from among 526 victims. Of all serious AIDS cases, 47.3 percent are in the New York metropolitan area….All it seems to take is the one wrong fuck. That’s not promiscuity – that’s bad luck.

There is no question that if this epidemic was happening to the straight, white, non-intravenous-drug-using middle class, money would have been put into use almost two years ago, when the first alarming signs of this epidemic were noticed by Dr. Alvin Friedman-Kien and Dr. Linda Laubenstein at New York University Hospital.

During the first two weeks of the Tylenol scare, the United States Government spent $10 million to find out what was happening.…

I am sick of closeted gays. It’s 1983 already, guys, when are you going to come out? By 1984 you could be dead. I am sick of guys who moan that giving up careless sex until this blows over is worse than death. How can they value life so little and cocks and asses so much? Come with me, guys, while I visit a few of our friends in Intensive Care at NYU. Notice the looks in their eyes, guys. They’d give up sex forever if you could promise them life. …I am sick of guys who think that all being gay means is sex in the first place. I am sick of guys who can only think with their cocks.

The second “original sin”—likely stemming from the first one—was failure to disclose the risks of blood transfusions to unsuspecting surgical patients, especially when undergoing elective procedures, or non-emergent procedures. The courts had established in 1976—five years before the first article on AIDS—that healthcare providers had a duty to warn (see further), which was also violated. All healthcare providers were aware that AIDS was a blood borne virus before it was isolated as LAV (Barre-Sinoussi et al. 1983) or HTLV III (Popovic et al. 1984), and knew that there was no screening being implemented. Thus, the first line of defense for reducing transfusion-AIDS was informed consent and disclosure of transfusion-AIDS as a risk, and providing the option of autologous transfusion. This did not become widespread practice until it was too late. Moreover, patients who had been infected and developed AIDS, as depicted in the film, were routinely not told they had been transfused with unsafe blood, which meant they could infect others unknowingly.

Similarly, hemophiliac patients were not warned about the risks of taking Factor VIII until it was too late (IOM 1995); many hemophiliacs even questioned their

⁴See also Clews, Colin (July 6, 2015) Discussion and Reprint of article by Kramer, Larry (March 1983) https://www.gayinthe80s.com/2015/07/1983-hivaids-1112-and-counting/.
personal physicians, or patient foundations about risks, and were encouraged that the risks were overblown when directed plasma donor programs could have been an alternative (IOM 1995). Risk disclosure of procedures or therapy, in the absence of any defined guideline or policy, is up to medical judgment. Disclosure of the risks of transfusion-AIDS ultimately became complicated in a risk averse, for-profit medical model, and in the setting of public hysteria over HIV/AIDS.

As discussed in the History of Medicine section, early AIDS practitioners were ostracized by their peers when they wanted to devote their interests to AIDS; this led to a clinical care vacuum for early AIDS patients, and also influenced institutional budgets with respect to resource allocation for AIDS care.

The failure to warn about risks about transfusion-AIDS was summarized this way by the Institute of Medicine (IOM) in its scathing report on its investigation into the epidemic of transfusion-AIDS cases, *HIV and the Blood Supply* (IOM 1995):

> The introduction of HIV into the blood supply posed powerful dangers to those individuals with hemophilia and recipients of blood transfusions during the early years of the epidemic. During the period from 1982 to 1984, before the AIDS virus was finally identified and a test developed to determine its presence, there was considerable speculation about whether the blood supply could be a vector for this new, fatal infection. As evidence about risk developed, consumers of blood and blood products—as well as their physicians—found themselves in a complex dilemma. Continued use of blood and blood products might heighten the risk of acquiring a new disease. Reducing or discouraging the use of blood products might increase the morbidity and mortality… Approximately half of the 16,000 hemophiliacs and over 12,000 recipients of blood transfusions became infected with HIV during this period. More effective communication of the risks associated with blood and blood products and the opportunity to choose from a wide spectrum of clinical options might have averted some of these infections…

Several social and cultural impediments in the relationships between patients and physicians interfered with the communication of information about the risks associated with using blood and blood products. These included the tendency of physicians to not discuss, or to downplay and deny, the risk of AIDS;… the difficulties of communicating dire news to patients; and the problems associated with communicating uncertainty…. Physicians often responded to the initial questions of patients with reassurances that the risk was not serious, that the patient was overreacting… Or, the physician conveyed the impression that the risk was a problem associated with homosexual behavior [only].

Invalid Consent, Nondisclosure and Withholding of Information

Obviously, no patient who required blood products or a potential blood transfusion in the period before 1985, when the blood industry finally began screening for HIV/AIDS, had informed consent about the risk of HIV/AIDS through the blood supply. Unfortunately, informed consent served as both the first, and last, line of defense in the early years of the epidemic. Unlike the physicians involved in the Tuskegee study (see Chap. 1), who practiced medicine in the pre-informed consent era, there was no excuse by 1981, when AIDS was first described. By then, informed consent in medicine was legally and ethically required (Katz 1986; Faden and Beauchamp 1985), and even the judicial council of the American Medical
Association stated in 1981 that “Informed consent is a basic social policy… Social policy does not accept the paternalistic view that the physicians may remain silent because divulgence might prompt the patient to forego needed therapy.” But the IOM discovered that (IOM 1995):

[In some special medical practices, such as hemophilia and transfusion medicine, [disclosure of risks] was not fully adhered to until the early 1980s… [and] the practice of hemophilia and transfusion medicine was somewhat removed from recognized medical norms….The Committee also found that some physicians were reluctant to discuss bad news, including a prognosis with dire implications, once symptoms of AIDS began to occur in their patients. Even when confronted with initial symptoms of AIDS, the physician’s message to his patient sometimes was to not worry….The appearance of AIDS in a previously healthy individual with hemophilia became a frightening experience for physicians [and once] physicians realized that the majority of individuals with severe hemophilia were infected with HIV, they became uncomfortable with discussing the implications of the widespread infection with their patients….

The IOM concluded (IOM 1995):

[There were serious shortcomings in effective communication of risks associated with the use of blood and blood products. The Committee’s analysis of physician–patient communications at the beginning of the AIDS era illustrates the tragedies that can accompany silence about risks…. One powerful lesson of the AIDS crisis is the importance of telling patients about the potential harms of the treatments that they are about to receive.

With respect to hemophilia, there was also a failure of the National Hemophilia Foundation’s (NHF) medical advisory council to warn patients about risks. Its clinical practice guidelines were compromised by the organization’s “financial connections to the plasma fractionation industry…The NHF provided treatment advice, not the information on risks and alternatives that would enable physicians and patients to decide for themselves on a course of treatment. Hemophilia patients did not have the basis for informed choice about a difficult treatment decision” (IOM 1995).

The Public Health Theater

Public health ethical violations at the health policy level led to widespread contamination of the public blood supply and no warning to the public that the blood supply was unsafe. The IOM’s findings were alarming and damning. There was enough evidence by 1982, and irrefutably, by early 1983, that AIDS was a blood borne virus that could be transmitted through blood transfusion. By 1984, 12,000 cases of transfusion-HIV infections had occurred, which meant that infected patients had also likely spread the virus to untold thousands through unsafe sex or other means.

Despite the evidence that AIDS could be transmitted through transfusion, the blood industry, which comprised of multiple agencies, declined to accept the CDC recommendations to implement a number of wise strategies that would have significantly reduced transfusion-AIDS cases. Each recommended strategy is outlined here.
Donor Screening and Deferral

Donor screening and deferral involved screening interviews, questionnaires, or medical exams, that would identify high-risk donors so that they could be coded as either “not for transfusion” or rejected as donors. Lab tests on donor blood that had another infectious disease could also have been used as a “flag” for blood that was “not for transfusion”. The history of donor pools and blood donation is vast, and will not be discussed here. However, it was clear for years that paid blood donors (prisoners, mental health patients, IV drug users) were typically higher risk than unpaid volunteers, and so could have been easily flagged as higher risk. Before 1973, blood was routinely screened for syphilis (see Chap. 1), and hepatitis and was not used if it was infected, but after this timeframe, it was labelled merely as paid donor or unpaid donor, and typically not screened; most Factor VIII was derived from the paid donor pool (IOM 1995).

On January 4, 1983, there was an historic contentious meeting of stakeholders surrounding the blood supply, which was a disastrous meeting in which no one could agree to any standards or guidelines. The meeting is re-enacted in the film, and was the scene in which Don Francis yells in frustration: “How many dead hemophiliacs do you need?” On January 6, 1983, Francis suggested deferring any blood donors who were high-risk (IV drug use; unprotected sex/sexually promiscuous; have Hepatitis B, or have lived in Haiti), and estimated that this would have eliminated 75% of infected blood donors (IOM 1995).

In 1976, in a landmark “duty to warn” case involving the duty to breach confidentiality in order to warn a third party of a known danger (see further), the courts made clear that “privacy ends where the public’s peril begins” (Tarasoff 1976). Nevertheless, the IOM found in 1995 that “special interest politics” interfered with sound public health policy (IOM 1995):

Some people viewed direct questioning about sexual behavior and drug use as a violation of an individual’s right to privacy. Public health officials countered by saying that the individuals’ rights were less important than the collective public health. Many in the gay community objected to direct questioning and donor deferral procedures as discriminatory and persecutory. Many in the blood bank community questioned the appropriateness of asking direct or indirect questions about a donor’s sexual preference. Other individuals and organizations were concerned about providing the public with information about AIDS that might scare them away from donating blood.…

The blood banks were worried about optics and losing a motivated donor pool they depended on, while the National Gay Task Force, a strong political lobby, were against banning blood donation from homosexual men. Blood banks were worried that donor screening/deferral strategies might also “out” gay men who were closeted, which had serious social repercussions (IOM 1995). But as the courts had ruled by that time, there were limits to autonomy, privacy and confidentiality when the public’s health was at risk in a public health emergency or epidemic, which this was. Proposals for “donor deferral” were also rejected, in which donors themselves read a questionnaire that surveys if they are high-risk and opt out themselves (IOM 1995).
Surrogate Testing Using the Hepatitis B Test

If the blood industry did not like the idea of donor questionnaires and interviews, the CDC had another idea that would protect privacy and confidentiality, which was called “surrogate testing”. At the same disastrous January 4, 1983, meeting, the CDC proposed this idea, too. By merely screening donors for the Hepatitis B virus, it would also catch a large percentage infected with the AIDS virus. Donors who tested positive for Hepatitis B could reasonably be considered too high risk to donate blood. But, alas, surrogate testing was not considered cost-effective, and on January 28, 1983, “the American Blood Resources Association (ABRA), recommended against large-scale surrogate testing of donated blood until ABRA had evaluated its feasibility” (IOM 1995). By June 22, 1983, the American Association of Blood Banks, the Council of Community Blood Centers, and the American Red Cross jointly stated that the risk of AIDS was too low to justify screening strategies that would “disrupt the nation’s blood donor system” (IOM 1995), while gay activists were against screening measures that could increase discrimination. The only blood bank that began to screen using a surrogate test was the Stanford University Blood Bank, which began screening blood July 1, 1983. Nonetheless, public anxiety over AIDS was mounting (Daly 1983).

Warning the Public About Transfusion-AIDS

Incredibly, even the suggestion of direct warnings to the public about transfusion-AIDS was summarily rejected by the blood industry. Warning the public about the possibility of AIDS through transfusion and educating them about directed or autologous donation was the minimal requirement, and not doing so clearly violated the Duty to Warn (see further). According to the IOM report (IOM 1995):

The blood industry was concerned about providing information on AIDS to the public lest donors take fright and stop donating blood. In January 1983, The [American Association of Blood Banks’ (AABB)’s] Committee on Transfusion Transmitted Diseases [stated] “we do not want anything we do now to be interpreted by society (or by legal authorities) as agreeing with the concept—as yet unproven—that AIDS can be spread by blood”.

The IOM also found that politics, competition for resources in the parsimonious Reagan administration, and hidden agendas interfered with sound public health policy. For example, a January 26, 1983, interoffice memo between two American Red Cross officials stated (IOM 1995):

CDC is likely to continue to play up AIDS – it has long been noted that CDC increasingly needs a major epidemic to justify its existence…especially in light of Federal funding cuts.

Even after the HTLV-III virus was isolated by Gallo in 1984 (see earlier), no interim strategies to safeguard the blood supply were implemented, including heat-treating Factor VIII to kill the AIDS virus, which was suggested in 1983, confirmed to work well by 1984 (IOM 1995), but not required by the FDA until 1989, when it finally recalled all untreated Factor VIII.
Ultimately, widespread screening of the blood supply did not occur until 1985, when testing was finally developed (see earlier). Even so, untested blood continued to be used even after the ELISA testing was developed (IOM 1995). However, with the first generation of HIV tests (see earlier), HIV-positive donors could still squeak by if they donated too early after exposure, given the several weeks’ window it could take for antibodies to develop.

**Failure to Notify At-Risk Blood Recipients**

Even with the delays in screening the blood supply, there was no program in place to notify recipients of infected blood that they had been infected, a situation conveyed in a powerful scene in *And the Band Played On*, in which a patient (played by Swoosie Kurtz) became infected when she had cardiac surgery, but was never told why she had opportunistic infections. When this scene aired in 1993, many recipients of tainted blood had not yet been made aware of the risk of AIDS, the risks of transmission to their partners through sex, maternal transmission at birth, or postnatal transmission through breastfeeding. These critical “lookbacks” had not begun until 1991, which was egregious. Yet by 1985, it was clear that transfusion-AIDS was a big problem. It was also clear that infected recipients of blood products could infect intimate partners, and could lead to maternal AIDS transmissions. In 1988 the Reagan administration asked the Department of Health and Human Services (DHHS) to find a way to trace all recipients of possibly infected blood products to inform them that they are at-risk so they can get tested, and practice safe sex. But for reasons not clear, it was not until September 1991 that any type of “lookback” program was put into place. The FDA did, however, contact recipients of any “repeat blood donor” who had newly tested HIV-positive.

The IOM stated (1995):

Individuals with hemophilia, transfusion recipients, and their families have raised serious concerns about why there were not better safeguards and warning systems to protect them from viruses transmitted by blood products…Were consumers of blood and blood products appropriately informed of the possible risks associated with blood therapy and were alternatives clearly communicated?…Perhaps no other public health crisis has given rise to more lasting anger and concern than the contamination of the nation’s blood supply with HIV…. The safety of the blood supply is a shared responsibility of many organizations—the plasma fractionation industry, community blood banks, the federal government, and others…. When confronted with a range of options … to reduce the probability of spreading HIV through the blood supply, blood bank officials and federal authorities consistently chose the least aggressive option that was justifiable…Interagency squabbling, lack of coordination, and miscommunication …[was the] most important organizational factor at work in explaining the cautious choices of public health authorities with regard to donor screening and deferral….The FDA instituted the “lookback” recommendation in 1991, at least six years after it was clear that AIDS had a long incubation period during which the patient could transmit HIV through sexual contact or contact with blood.
Catastrophically (IOM 1995):

Blood banks, government agencies, and manufacturers were unable to reach a consensus on how extensively to screen for high-risk donors in order to substantially reduce the risk of HIV transmission through the blood supply. There was no consensus at the January 4, 1983, meeting, and it appears that no individual or organization took the lead...Lack of agreement on the interpretation of scientific data, pressure by special interest groups, organizational inertia...resulted in a delay of more than one year in implementing strategies to screen donors for risk factors associated with AIDS...[A] failure of leadership...during the period from 1982 to 1984... led to incomplete donor screening policies, weak regulatory actions, and insufficient communication to patients about the risks of AIDS.

The Duty to Warn is discussed in Chap. 1 and elsewhere.

The Research Ethics Theater

And the Band Played On devotes considerable time to the Montagnier-Gallo controversy, which is fully discussed earlier. Research misconduct and violations of professional ethics in the research setting ultimately affect patient care because it leads to delays in necessary translational research. Gallo had been sent samples of LAV to verify, which he did not do. Instead, he confused and delayed progress in AIDS research by naming a different virus (HTLV III) which wound up being LAV after all. Gallo’s mischaracterization of LAV (which he currently admits was unintentionally) and manipulation of his own data (which he admits occurred unintentionally) was fueled by his desire to usurp credit for the discovery of HTLV-III, and be the first to patent the HTLV-III (later HIV) test. But in the process, may have delayed the development of an LAV test by at least a year, which could have screened blood donors earlier, and may have also sped up development of a treatment. It is not possible to quantify what Gallo’s actions ultimately cost in lives from the standpoint of avoidable infections or earlier treatment. Professionalism and collegiality are discussed later in this book (Chaps. 8 and 9).

Most of all, as soon as AIDS was labelled a “gay disease”, it became less desirable as a research priority due to stigma and discrimination. The example of the Michael Gottlieb story (see under History of Medicine) is testament to how major academic research centers viewed AIDS research—they did not want to fund it or champion it. Nor did funding agencies.

And the Harms Go On: Post-Band Ethical Issues in HIV/AIDS

The film, And the Band Played On ends around 1984, and does not cover the eras of HIV testing or AZT. Testing raised many issues surrounding privacy and confidentiality as a result of the social stigma related to a positive test, which eventually led
to the passage of the HIPAA privacy rules that took effect in 2003. Throughout the mid-1980s and 1990s, many ethical debates raged over anonymous versus mandatory testing because of tensions between protecting autonomy and confidentiality and the duty to warn.

Meanwhile, access to treatment raised many issues surrounding health disparities, insurance coverage for AIDS patients, end of life care and palliative care, but these were much broader systemic issues that had to do with the discriminatory practices upon which the entire U.S. healthcare system was based (see Chap. 4). Conservative opposition to sex education and contraception also led to a ban on federal funding for safe sex education, which resulted in more HIV transmissions in teens and young adults. Similarly, although needle exchange programs flourished throughout Europe, there was resistance from all levels of government to initiate such programs in the United States. By the 1990s, AIDS “treatment activism” begins to emerge, as AIDS patients fought for access to experimental therapies and clinical trials as a means to accessing treatment.

Drug pricing for AZT (see earlier) also led to huge debates; AZT cost about $8000 annually in 1987, comparable to about $20,000 annually today. The cost of AZT treatment, in fact, drove researchers dealing with the global AIDS epidemic in poor countries to seek a cheaper maternal AIDS protocol, which resulted in the resignation of the editor of the New England Journal of Medicine at the time because AZT protocols designed to “undertreat” to save money was compared to a repeat of the Tuskegee study (see Chap. 1). Today, similar questions are being raised about the treatment costs of PrEP (see earlier), which is not reaching the populations the regimen was designed to protect.

From the time And the Band Played On aired in 1993 until 2008, healthcare reform in the United States had stalled. By the time healthcare reform became an election issue again in 2008 (thanks to the 2007 film, Sicko, discussed in Chap. 4), roughly one million people were living with HIV in the United States, and 21% were unaware of their serostatus. In 2010, the CDC estimated that 56,300 Americans were becoming infected with HIV each year, with approximately 18,000 deaths from AIDS annually—equal to six times the casualties on 9/11. Between 1981 and 2009, when the Affordable Care Act was passed, 60 million people globally had contracted HIV; 33 million were living with AIDS (2 million under age 15) and 25 million had died of AIDS, equal to the entire respective populations of several countries.

Lingering issues surrounding stigma and the duty to warn remained for years, but anonymous testing was abandoned in 37 U.S. states by the early 2000s when it was clear that the duty to warn and partner notification was a higher priority. Mandatory HIV screening in newborns mitigated the spread of pediatric AIDS while “opt out” testing policies in prenatal populations were successful in reducing maternal AIDS transmission. Finally, the AIDS crisis led to changes in access to experimental treatments and clinical trials that ultimately led to a sea change in expedited clinical research overall.
Conclusions

When planning a healthcare ethics curriculum that covers the history of harms to vulnerable populations, teaching the early history of HIV/AIDS is as critical now as teaching about Nazi medical experiments or the Tuskegee study (see Chap. 1). Within the HIV/AIDS story lies a significant chapter in the “history of healthcare ethics”. When the first bioethics courses began to be taught in the 1970s, we were about 30 years away from the liberation of the Nazi death camps and the Nuremberg trials. When the Tuskegee study began to be taught to bioethics students in the mid-1980s, we were only about a decade out from the exposure of that notorious trial. We are now further away from the early days of AIDS than we were from either the Nuremberg trials or Tuskegee study when they became a fixed menu item on the healthcare ethics curriculum. When the story of HIV/AIDS is taught to healthcare trainees today, it leads to many epiphanies because this history is just not taught—even to medical students studying HIV/AIDS as part of their infectious disease units. Until recently, experts in HIV/AIDS in charge of medical school curriculums had very clear memories of the 1980s and 1990s, but many did not want to “relive” it, sticking to solely the treatment advances narrative. It’s likely that healthcare professionals on the front lines in those years suffered moral injury and are unable to revisit the ethical violations they witnessed during this period. However, the discriminatory attitudes toward the LBGT community have not disappeared, and are still playing out. Fortunately, HBO’s decision to keep the film, And the Band Played On faithful to Shilts’ book, and not dilute it with needless subplots and melodrama, makes it an enduring docudrama that has immense pedagogic utility for medical educators and should become a fixed menu item, too.

Theatrical Poster

And the Band Played On (1993)

Based on: And the Band Played On: People, Politics and the AIDS Epidemic by Randy Shilts
Screenplay by: Arnold Schulman
Directed by: Roger Spottiswoode
Starring: Matthew Modine, Alan Alda, Ian McKellen, Lilly Tomlin, Richard Gere
Theme music composer: Carter Burwell
Country of Origin: United States
Producers: Sarah Pillsbury, Midge Sanford
Running time: 141 min
Distributor: HBO
Original Network: HBO
Original Release: September 11, 1993
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