How AIDS Changed America

The plague years: It brought out the worst in us at first, but ultimately it brought out the best, and transformed the nation. The story of a disease that left an indelible mark on our history, our culture and our souls.

By David Jefferson

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May 15, 2006 issue - Jeanne White-Ginder sits at home, assembling a scrapbook about her son, Ryan. She pastes in newspaper stories about his fight to return to the Indiana middle school that barred him in 1985 for having AIDS. She sorts through photos of Ryan with Elton John, Greg Louganis and others who championed his cause. She organizes mementos from his PBS special, "I Have AIDS: A Teenager's Story."

"I just got done with his funeral. Eight pages. That was very hard," says White-Ginder, who buried her 18-year-old son in 1990, five-and-a-half years after he was diagnosed with the disease, which he contracted through a blood product used to treat hemophiliacs. The scrapbook, along with Ryan's bedroom, the way his mother left it when he died, will be part of an exhibit at the Children's Museum of Indianapolis on three children who changed history: Anne Frank. Ruby Bridges. And Ryan White. "He put a face to the epidemic, so people could care about people with AIDS," his mother says.

At a time when the mere threat of avian flu or SARS can set off a coast-to-coast panic—and prompt the federal government to draw up contingency plans and stockpile medicines—it's hard to imagine that the national response to the emergence of AIDS ranged from indifference to hostility. But that's exactly what happened when gay men in 1981 began dying of a strange array of opportunistic infections. President Ronald Reagan didn't discuss AIDS in a public forum until a press conference four years into the epidemic, by which time more than 12,000 Americans had already died. (He didn't publicly utter the term "AIDS" until 1987.) People with the disease were routinely evicted from their homes, fired from jobs and denied health insurance. Gays were demonized by the extreme right wing: Reagan adviser Pat Buchanan editorialized in 1983, "The poor homosexuals—they have declared war against nature, and now nature is exacting an awful retribution." In much of the rest of the culture, AIDS was simply treated as the punch line to a tasteless joke: "I just heard the Statue of Liberty has AIDS," Bob Hope quipped during the rededication ceremony of the statue in 1986. "Nobody knows if she got it from the mouth of the Hudson or the Staten Island Fairy." Across the river in Manhattan, a generation of young adults was attending more funerals than weddings.

As AIDS made its death march across the nation, killing more Americans than every conflict from World War II through Iraq, it left an indelible mark on our history and culture. It changed so many things in so many ways, from how the media portray homosexuality to how cancer patients deal with their disease. At the same time, AIDS itself changed, from a disease that killed gay men and drug addicts to a global scourge that has decimated the African continent, cut a large swath through black America and infected almost as many women as men worldwide. The death toll to date: 25 million and counting. Through the crucible of AIDS, America was forced to face its fears and prejudices—fears that denied Ryan White a seat in school for a year and a half, prejudices that had customers boycotting restaurants with gay chefs. "At first, a ton of people said that whoever gets AIDS deserves to have AIDS, deserves to literally suffer all the physical pain that the virus carries with it," says Tom Hanks, who won an Oscar for playing a gay lawyer dying of the disease in 1993's "Philadelphia." "But that didn't hold." Watching a generation of gay men wither and die, the nation came to acknowledge the humanity of a community it had mostly ignored and reviled. "AIDS was the great unifier," says Craig Thompson, executive director of AIDS Project Los Angeles and HIV-positive for 25 years.

Without AIDS, and the activism and consciousness-raising that accompanied it, would gay marriage even be up for debate today? Would we be welcoming "Will & Grace" into our living rooms or weeping over "Brokeback Mountain"? Without red ribbons, first worn in 1991 to promote AIDS awareness, would we be
Donning rubber yellow bracelets to show our support for cancer research? And without the experience of battling AIDS, would scientists have the strategies and technologies to develop the antiviral drugs we’ll need to battle microbial killers yet to emerge?

AIDS, of course, did happen. "Don't you dare tell me there's any good news in this," says Larry Kramer, who has been raging against the disease—and those who let it spread unchecked—since it was first identified in 1981. "We should be having a national day of mourning!" True. But as we try to comprehend the carnage, it's impossible not to acknowledge the displays of strength, compassion and, yes, love, that were a direct result of all that pain and loss. Without AIDS, we wouldn't have the degree of patient activism we see today among people with breast cancer, lymphoma, ALS and other life-threatening diseases. It was Kramer, after all, who organized 10,000 frustrated AIDS patients into ACT UP, a street army chanting "Silence equals death" that marched on the White House and shut down Wall Street, demanding more government funding for research and quicker access to drugs that might save lives. "The only thing that makes people fight is fear. That's what we discovered about AIDS activism," Kramer says.

Fear can mobilize, but it can also paralyze—which is what AIDS did when it first appeared. And no one—not the government, not the media, not the gay community itself—reacted fast enough to head off disaster. In the fiscally and socially conservative climate of Reagan's America, politicians were loath to fund research into a new pathogen that was killing mostly gay men and intravenous drug users. "In the first years of AIDS, I imagine we felt like the folks on the rooftops during Katrina, waiting for help," says Dr. Michael Gottlieb, the Los Angeles immunologist credited as the first doctor to recognize the looming epidemic. When epidemiologist Donald Francis of the federal Centers for Disease Control in Atlanta tried to get $30 million in funding for an AIDS-prevention campaign, "it went up to Washington and they said f--- off," says Francis, who quit the CDC soon after, defeated.

"Gay Cancer," as it was referred to at the time, wasn't a story the press wanted to cover—especially since it required a discussion of gay sex. While the media had a field day with Legionnaire's disease, toxic shock syndrome and the Tylenol scare, few outlets paid much attention to the new syndrome, even after scores of people had died. The New York Times ran fewer than a dozen stories about the new killer in 1981 and 1982, almost all of them buried inside the paper. (NEWSWEEK, for that matter, didn't run its first cover story on what "may be the public-health threat of the century" until April 1983.) The Wall Street Journal first reported on the disease only after it had spread to heterosexuals: NEW, OFTEN-FATAL ILLNESS IN HOMOSEXUALS TURNS UP IN WOMEN, HETEROSEXUAL MALES, read the February 1982 headline. Even the gay press missed the story at first: afraid of alarming the community and inflaming antigay forces, editors at the New York Native slapped the headline DISEASE RUMORS LARGELY UNFOUNDED atop the very first press report about the syndrome, which ran May 18, 1981. There were a few notable exceptions, particularly the work of the late Randy Shilts, an openly gay journalist who convinced his editors at the San Francisco Chronicle to let him cover AIDS as a full-time beat: that reporting led to the landmark 1987 book "And the Band Played On," a detailed account of how the nation's failure to take AIDS seriously allowed the disease to spread exponentially in the early '80s.

Many gay men were slow to recognize the time bomb in their midst, even as people around them were being hospitalized with strange, purplish skin cancers and life-threatening pneumonia. Kramer and his friends tried to raise money for research during the 1981 Labor Day weekend in The Pines, a popular gay vacation spot on New York's Fire Island. "When we opened the collection boxes, we could not believe how truly awful the results were," says Kramer. The total? $769.55. "People thought we were a bunch of creeps with our GIVE TO GAY CANCER signs, raining on the parade of Pines' holiday festivities." The denial in some corners of the gay community would continue for years. Many were reluctant to give up the sexual liberation they believed they’d earned: as late as 1984, the community was bitterly debating whether to close San Francisco's gay bathhouses, where men were having unprotected sex with any number of partners in a single night.

With death a constant companion, the gay community sobered up from the party that was the '70s and rose to meet the unprecedented challenge of AIDS. There was no other choice, really: they had been abandoned by the nation, left to fend for themselves. "It's important to remember that there was a time when people did not want to use the same bathroom as a person with AIDS, when cabdrivers didn't want to pick up patients who had the disease, when hospitals put signs on patients' doors that said WARNING. DO NOT ENTER," recalls Marjorie Hill, executive director of Gay Men's Health Crisis in New York.
Organizations like GMHC sprang up around the country to provide HIV patients with everything from medical care to counseling to food and housing. "Out of whole cloth, and without experience, we built a healthcare system that was affordable, effective and humane," says Darrel Cummings, chief of staff of the Los Angeles Gay & Lesbian Center. "I can't believe our community did what it did while so many people were dying." Patients took a hands-on approach to managing their disease, learning the intricacies of T-cell counts and grilling their doctors about treatment options. And they shared what they learned with one another. "There's something that a person with a disease can only get from another person with that disease. It's support and information and inspiration," says Sean Strub, who founded the magazine Poz for HIV-positive readers.

It took a movie star to get the rest of the nation's attention. In the summer of 1985, the world learned that Rock Hudson—the romantic leading man who'd been a symbol of American virility—was not only gay, but had full-blown AIDS. "It was a bombshell event," says Gottlieb, who remembers standing on the helipad at UCLA Medical Center, waiting for his celebrity patient to arrive, as news helicopters circled overhead. "For many Americans, it was their first awareness at all of AIDS. This prominent man had been diagnosed, and the image of him looking as sick as he did really stuck." Six years later, basketball legend Magic Johnson announced he was HIV-positive, and the shock waves were even bigger. A straight, healthy-looking superstar athlete had contracted the "gay" disease. "It can happen to anybody, even me, Magic Johnson," the 32-year-old announced to a stunned nation, as he urged Americans to practice safe sex.

Given the tremendous stigma, most well-known public figures with AIDS tried to keep their condition a secret. Actor Brad Davis, the star of "Midnight Express," kept his diagnosis hidden for six years, until he died in 1991. "He assumed, and I think rightly so, that he wouldn't be able to find work," says his widow, Susan Bluestein, a Hollywood casting director. After Davis died, rumors flew that he must have been secretly gay. "That part of the gossip mill was the most hurtful to me and my daughter," says Bluestein, who acknowledges in her book "After Midnight" that her husband was a drug addict and unfaithful—but not gay.

With the disease afflicting so many of their own, celebrities were quick to lend support and raise money. Elizabeth Taylor was among the first, taking her friend Rock Hudson's hand in public, before the TV cameras and the world, to dispel the notion that AIDS was something you could catch through casual contact. Her gesture seems quaint today, but in 1985—when the tabloids were awash with speculation that Hudson could have infected actress Linda Evans by simply kissing her during a love scene in "Dynasty"—Taylor's gesture was revolutionary. She became the celebrity face of the American Foundation for AIDS Research. "I've lost so many friends," Taylor says. "I have so many friends who are HIV-positive and you just wonder how long it's going to be. And it breaks your heart."

Behind the scenes, Hollywood wasn't nearly as progressive as it likes to appear. John Erman recalls the uphill battle getting the 1985 AIDS drama, "An Early Frost," on TV. "The meetings we had with NBC's Standards and Practices [the network's censors] were absolutely medieval," says Erman. One of the censors' demands: that the boyfriend of the main character be portrayed as "a bad guy" for infecting him: "They did not want to show a positive gay relationship," Erman recalls. Ultimately, with the support of the late NBC Entertainment president Brandon Tartikoff, Erman got to make the picture he wanted—though major advertisers refused to buy commercial time during the broadcast. Within a decade, AIDS had changed the face of television. In 1991, "thirtysomething" featured a gay character who'd contracted the disease. And in 1994, on MTV's "The Real World," 23-year-old Pedro Zamora, who died later that same year, taught a generation of young people what it meant to be HIV-positive.

If TV was slow to deal with AIDS, cinema was downright glacial. "Longtime Companion," the first feature film about the disease, didn't make it to the screen until 1990, nine years into the epidemic. "There was a lot of talk before the movie came out about how this was going to hurt my career, the same way there was talk about Heath Ledger in 'Brokeback Mountain'," says Bruce Davison, who received an Oscar nomination for his role. As for "Philadelphia," Hanks is the first to admit "it was late to the game."

Broadway was the major exception when it came to taking on AIDS as subject matter—in part because so many early casualties came from the world of theater. "I remember in 1982 sitting in a restaurant with seven friends of mine. All were gay men either working or looking to work in the theater, and we were
talking about AIDS," recalls Tom Viola, executive director of Broadway Cares/Equity Fights AIDS. "Of those eight guys, four are dead, and two, including myself, are HIV-positive." By the time Tony Kushner's Pulitzer Prize-winning "Angels in America" made its Broadway debut in 1993, some 60 plays about the disease had opened in New York. Producer Jeffrey Seller remembers how he was told he "could never do a show on Broadway that's about, quote unquote, AIDS, homosexuality and drug addiction." He's talking about "Rent," which a decade later still draws capacity crowds.

The world of "Rent" is something of an artifact now. Just before it hit Broadway in 1996, scientists introduced the antiretroviral drug cocktails that have gone on to extend the lives of millions of patients with HIV. Since then, the urgency that once surrounded the AIDS fight in the United States has ebbed, as HIV has come to be seen as a chronic, rather than fatal, condition. But the drugs aren't a panacea—despite the fact that many people too young to remember the funerals of the '80s think the new medications have made it safe to be unsafe. "Everywhere I go, I'm meeting young people who've just found out they've been infected, many with drug-resistant strains of the virus," says Cleve Jones, who two decades ago decided to start stitching a quilt to honor a friend who had died of AIDS. That quilt grew to become an iconic patchwork of more than 40,000 panels, each one the size of a grave, handmade by loved ones to honor their dead. Ever-expanding, it was displayed several times in Washington, transforming the National Mall into what Jones had always intended: a colorful cemetery that would force the country to acknowledge the toll of AIDS. "If I'd have known 20 years ago that in 2006 I'd be watching a whole new generation facing this tragedy, I don't think I would have had the strength to continue," says Jones, whose own HIV infection has grown resistant to treatment.

Inner strength is what has allowed people living with HIV to persevere. "They think I'm gonna die. You know what, they better not hold their breath," Ryan White once told his mother. Though given six months to live when he was diagnosed with HIV, Ryan lived five and a half years, long enough to prod a nation into joining the fight against AIDS. When he died in 1990 at the age of 18, Congress named a new comprehensive AIDS funding act after him. But the real tribute to Ryan has been the ongoing efforts of his mother. "I think the hostility around the epidemic is still there. And because of religious and moral issues, it's been really hard to educate people about this disease and be explicit," says White-Ginder, who continues to give speeches about watching her son live and die of AIDS. "We should not still be facing this disease." Sadly, we are.

*With Ramin Setoodeh*

*Correction: The original version of this report incorrectly stated that Ryan White's funeral took place in 1991. In fact, it was in 1990.*

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