



AIDS: Where we stand, what we've learned

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AIDS: Where we stand, what we've learned -- After 25 years, 25 million dead

By BILL ERVOLINO, STAFF WRITER

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Twenty-five years ago, scientists reported that a handful of young gay men had died of the same rare form of pneumonia. Stranger still: Their immune systems had been decimated.

Within weeks, as the number of cases doubled, then tripled, researchers at the Centers for Disease Control in Atlanta scrambled to contain the killer they feared would grow into a global epidemic.

It was the summer of 1981 and the disease was so new it had yet to be named. But they were already too late to stop it.

Just months after the first reports of what would come to be known as AIDS, Francisco Guzman received a frantic call. "The mother of a high school friend phoned to say that Joey was very sick," the North Bergen resident remembers. "His official diagnosis was 'Fever of Unknown Origin.'

"I rushed to his room at St. Vincent's hospital in Manhattan, and it was like NASA in there. Everyone was dressed in white protective suits, gloves, goggles, masks over their faces. I had never seen anything like it. [The orderlies] wouldn't even come into the room with his food. They left the trays outside his door."

Guzman, now 48 and director of Hudson County Operations for the American Red Cross, says his friend was "one of the lucky ones." He lived another three years, unusual at that time, because his mother made him eat and made him fight.

At his funeral, only the people who knew him well knew what he had died of. "To everyone else it was cancer," Guzman says. "By then, people were calling it the gay plague. Cancer sounded better."

Over the next quarter-century AIDS would realize the worst fears of CDC researchers, claiming the lives of 25 million men, women and children. It tore families apart, brought together people who might never have met and provided us with lessons that many Americans have already forgotten: that we were unprepared for the emergence of a deadly new virus, that our responses to it were woefully inadequate and that it could happen all over again.

Three years after those initial deaths set off alarms at the CDC, 1,100 more were dead, thousands more were sick and the nation's blood supply was contaminated.

"By then, so much had changed," says Guzman, who began volunteering to help AIDS patients at FAITH Services in Hoboken. "AIDS had a name, but it was more than that. It was political. People were mad."

The anger over AIDS pitted incensed activists against the media (which they felt had underreported the disease), the religious right (after the Rev. Jerry Falwell proclaimed the disease a judgment from God), the Catholic Church (for refusing to allow Catholics to use condoms) and President Ronald Reagan (who didn't mention the word "AIDS" in public until 1986).

"AIDS was treated like no other disease before or since," says Susan Stoveken, a supervisor at New Jersey Buddies, an AIDS resource and support network in Hackensack.

Few in the suburbs would acknowledge the epidemic. "Gays, drugs, sexual transmission ... these were all taboo subjects that no one wanted to talk about," she says. "To most people, AIDS was something that was happening somewhere else."

Fewer than 7,000 cases of HIV/AIDS have been reported in North Jersey since 1981. But those numbers have never painted an accurate picture of AIDS in the region because many gay men early on in the crisis went for AIDS tests and treatment in New York, and were counted there. In New York, they found anonymity and better medical care, Stoveken says.

"If you were sick and you had money, good medical coverage, and friends in New York, you were treated in New York," she says.

Today, people in the suburbs continue to worry about anyone finding out they have AIDS. "I still talk to people who say they go to New York, or to Bergen residents who go to Passaic to be tested and treated," Stoveken says.

In 1985, the first International AIDS Conference was held in Atlanta. But that landmark meeting was overshadowed by two other stories that thrust AIDS onto the front pages of newspapers.

The first was the news that actor Rock Hudson was dying from "inoperable liver cancer" and was being treated at a Paris hospital known to be on the forefront of AIDS research. The second concerned Indiana teenager Ryan White, a hemophiliac who had been barred from school because he had AIDS.

The charismatic Hudson, a beloved movie star, and White, a wholesome, fresh-faced kid, provided two very different faces to the epidemic. Celebrities began speaking about AIDS and were photographed holding AIDS patients in hospitals, a radical act at the

time.

"AIDS patients had been so stigmatized, so ravaged by this disease, so sick, frightened, suffering so much, and no one would touch them," Guzman says. "Elizabeth Taylor and Princess Diana were able to be that gentle bridge, letting the public know it was OK to touch an AIDS patient, to comfort him. When that first photo came out of Diana holding a man with AIDS ... it was like an earthquake."

As more celebrities and hemophiliacs began dying of AIDS, the national mood switched from complacency to near-hysteria. Some worried the virus could be spread by mosquitoes.

"Now No One Is Safe from AIDS" was the blaring headline on the June 1985 cover of Life magazine.

"By this point," Guzman says, "the gay community was split into different camps; those who were convinced they were going to get sick and die, and those in denial."

Then there were the sick. "I saw it all: Patients who had no relatives around them because they didn't want their families to know; or families who found out their sons had AIDS and disowned them; or families who would rush in who didn't even know their son was gay or that the roommate was really his lover, and it was like speed-dial. All of these important conversations that had never taken place had to be done quickly, because there was no time left."

In the late 1980s, with no cure or vaccine on the horizon and a single treatment — AZT — that many AIDS patients were unable to afford, AIDS activists went nuclear in a series of disruptive, headline-grabbing protests in Washington, at New York's St. Patrick's Cathedral and on the floor of the New York Stock Exchange.

"Silence = Death" became the slogan of the New York-based AIDS Coalition to Unleash Power, ACT-UP, and its outrageous, anything-goes approach to activism proved, if nothing else, that it took the slogan seriously.

There was no way that Englewood resident Dawn Breedon could have missed the onslaught of news. "And yet," she says, "it never occurred to me that I was at risk."

As the 1990s began, a new wave of AIDS patients began to dominate the news, and Breedon became one of them. She was five months pregnant in 1991 when her brother called to tell her that a man she had dated 10 years earlier was dying of AIDS.

"I knew about AIDS, but I didn't think it could happen to me," said Breedon, now 46 and an advocate for inmates at the Bergen County Jail. "Even when I went for the test, my doctor discouraged me from having it, based on my lifestyle and the fact that I wasn't in a high-risk group."

Breedon tested positive for HIV and was told she should have an abortion. She refused.

Today, approximately 46 percent of the 40 million people with AIDS worldwide are women. New Jersey ranks first in the nation in the number of AIDS cases among women, and third in the number of children.

In North Jersey, women who were HIV-positive in the early 1990s often suffered in

silence. One woman was so afraid that her secret would be discovered, she boiled her empty AZT bottles to remove the laminated labels before tossing them into the trash.

"What if someone were to go through my garbage?" she asked a Record reporter at the time. "What if someone were to find out?"

Breedon's son was born HIV-positive in March 1992. Three years later, the boy's father waged a custody battle in which her HIV status was an issue. He later abducted and killed the child, poisoning him with a mixture of cyanide and ammonia. The father then committed suicide.

Breedon grieved for her son, but otherwise remained healthy into the new millennium.

"I'm what is known as a long-term non-progressor," she says, although she doesn't know for sure exactly when she was exposed.

Breedon declined to take any AIDS medications until this February, when tests indicated that the amount of virus in her body had dramatically increased. Her doctor put her on a regimen of drugs that AIDS patients call "cocktails," a combination of antivirals and other medications. She has since returned to normal.

While AIDS cocktails have been effective in slowing the virus, the side effects can be devastating.

"These drugs are toxic, and because of that, we don't see 'AIDS' on death certificates, anymore. We see heart failure, liver failure, lung failure, often due to side effects," says Steve Scheuermann, executive director of New Jersey Buddies. "Plus we have an aging population of people who have been dealing with this for 15 years or more, and they are dying of other things people in their 50s and 60s die from."

Thanks to these cocktails, the nation's AIDS death rate began to decline in 1996. Even as AIDS ravages Africa and spreads in China, U.S. deaths have remained fairly constant at about 17,000 per year for the past five years.

Still, new cases are reported every week. Scheuermann worries about those who are too young to remember the early years of AIDS.

"People become lax, a new generation of kids become sexually active, and people think it's something they don't have to worry about anymore," he says.

Today, he speaks frequently to students about AIDS. "The sad part," he says, "is that after the new drugs came on the market, young people were like, 'OK ... what's the big deal? We'll take a pill.' "

Still, in its first 25 years, AIDS has led to sweeping changes in how the blood supply is managed, and forced the Food and Drug Administration to streamline drug testing. The disease's impact on culture has also been enormous.

"Before AIDS, it was rare to hear gay men talking about marriage," he says. "AIDS changed all that. Men were denied access to their partner's hospital rooms and sometimes thrown out of their own homes after their partner died, because family members and the government did not recognize their relationships."

For Stoveken, the enduring legacy of AIDS is the people she has met because of it, particularly a 43-year-old client who died.

"I would spend time with her, bring her for her medical appointments, and we would talk all the time," she says. "It was an honor to know her. And when she died, I was there. She died in my arms."

Twenty-five million people have died of AIDS in the last 25 years, but the disease has touched many more, including the thousands who have volunteered at Buddies.

"When you see how people are so willing to give of themselves, to help people who are sick and alone," Stoveken says, "it really does renew your faith in mankind."

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AIDS timeline

Twenty-five years after the first reports of what would become known as AIDS, the origins of the disease are unclear, the cure elusive. A genetic analysis of HIV in 2003 suggests that it may have arrived in the United States about 1968 and spread undetected throughout the 1970s.

1981

First mention in the Centers for Disease Control's morbidity and mortality report of men who have died of an unknown illness. A high prevalence of a rare type of skin cancer — Kaposi's sarcoma — and pneumonia are found in young gay men in New York and California. By the end of the year 121 people have died of what has become known as "gay cancer."

1982

* CDC scientists establish the term acquired immune deficiency syndrome and determine that gays, IV drug users and hemophiliacs are at risk.

* AIDS had been detected on five continents.

1983

* Major outbreak of AIDS is reported in central Africa.

1984

* Cases of AIDS passed on through heterosexual intercourse begin to appear.

* The retrovirus responsible for AIDS, later named the human immunodeficiency virus, is discovered.

1985

- * U.S. blood banks begin screening for the virus and rejecting gay donors. The first HIV test is licensed by the Food and Drug Administration. The first International AIDS conference is held in Atlanta.

- * Rock Hudson, movie and television star, dies on Oct. 2.

1987

- * AZT becomes available to treat HIV sufferers and slows the course of AIDS.

- * 47,022 in the U.S. have been diagnosed with AIDS, 16,908 have died. Worldwide, there are 71,751 reported cases.

1988

- * The World Health Organization declares the first World AIDS Day on Dec. 1.

1990

- * Ryan White, who put a youthful face on AIDS as a hemophiliac infected through transfusions, dies on April 8 at 18.

1991

- * The red ribbon becomes an international symbol of AIDS awareness.

- * Magic Johnson suddenly retires from the NBA, announcing he is HIV-positive.

1992

- * AIDS becomes the leading cause of death for men 24 to 44 years old in the U.S.

1994

- * Using AZT to reduce the transmission of HIV from pregnant women to unborn fetuses is recommended.

- * More than 12 years after the discovery of AIDS, the U.S. government launches its first national media campaign explicitly promoting condoms.

1995

- * A new combination of drug therapies, dubbed "cocktails," proves effective in slowing AIDS progression; death rates begin to decline.

1996

- * FDA approves sale of first home HIV test kit.

1997

- * Annual U.S. death rates from AIDS dramatically fall for the first time.

* The United Nations announces that 40 million children will have lost one or both parents to AIDS by 2010.

1998

* The first full-scale trial of an HIV vaccine begins in the U.S.

* An HIV strain resistant to all inhibitor drugs currently on the market turns up in San Francisco.

1999

* AIDS becomes the fourth-biggest killer worldwide. Fourteen million have died; another 33 million are infected with HIV.

2003

* Five million people worldwide become infected with AIDS this year, the greatest one-year number since the epidemic began. Three million die from AIDS in this year.

2005

* A highly resistant strain of HIV linked to rapid progression to AIDS is identified in New York City.

2006

* Worldwide, 40 million are infected. This year, AIDS is expected to kill 2.8 million.

Illustrations/Photos: 1 - COLOR PHOTO ILLUSTRATION - ELAINE ISAACSON / STAFF ARTIST

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