The Anatomy of an Epidemic

By Laura Stephenson Carter
The story broke not with a bang but a whimper. Today, with 25 years of hindsight, it’s easy to see that the emergence of AIDS was one of the biggest health stories of the 20th century. But back in the early 1980s, doctors hadn’t yet put together scattered reports of unusual illnesses in New York, San Francisco, and other cities.

Young, previously healthy, gay men were complaining of fatigue, fever, diarrhea, unexplained weight loss, purplish lesions, respiratory ailments, and aggressive infections. Doctors were perplexed. Their patients were exhibiting symptoms normally found in immunocompromised patients. The purplish lesions were signs of Kaposi’s sarcoma, a rare but nonlethal cancer more likely to strike elderly men. The patients’ respiratory problems often worsened, turning into *Pneumocystis carinii* pneumonia (PCP), a rare disease first seen in orphanages in post-World War II Europe. Soon the men began exhibiting even more aggressive infections, including herpes; fungal growths; and toxoplasmosis, a parasitic infection of the central nervous system. They were getting sicker and sicker, wasting away, dying.

But the public health system was slow to react to these mysterious deaths. And peer-reviewed journals aren’t designed to spread news quickly; during the six months or more that it takes an article to go through the review and editing process, authors are barred from leaking news to the popular press.

But Dr. Andrew Saxon, a DMS graduate, and his colleagues at the University of California at Los Angeles managed to find a way around this problem. Theirs was the first official published report on what we now recognize as the AIDS epidemic.

**Breaking the silence**

Dr. Andrew Saxon, DMS ’70: now chief of clinical immunology and allergy and a professor of medicine at the University of California at Los Angeles (UCLA)

The patient had a “fungus ball on the end of his finger,” recalls UCLA immunologist Andrew Saxon. He was awed. “You didn’t see that except in bubble babies”—severely immunocompromised children who have to live inside a germ-free plastic bubble—“and in leukemics treated with intensive chemotherapy.”

It was the fall of 1980. The patient was a young, previously healthy, homosexual man. Over the next few months, Saxon and his colleague Dr. Michael Gottlieb treated four more gay men, all strangers to each other but all diagnosed with unusual infections. The five also developed pneumonia, which lung biopsies confirmed to be the rare PCP.
Alexandra Howell headed a Dartmouth Medical School research team that in 1997 was the first group to demonstrate that HIV infects normal tissues throughout the female reproductive tract. She currently studies HIV infection and the immune response to HIV proteins. *


* The effort to encapsulate in only a few words contributions by alumni and faculty to the fight against AIDS resulted in a few passages that don’t fully reflect some faculty members’ current work. Howell, since making the seminal 1997 finding described above, has studied heterosexual transmission of HIV, the influence of sex hormones on HIV infection, and the replication of HIV within the female reproductive tract.

They had a “profound T-cell deficiency,” too, says Saxon. T-cells, a type of white blood cell that fights infection, had just been discovered in the 1970s. “We knew there was something going on.”

By May 1981, Saxon and Gottlieb were sure they had an epidemic on their hands and were anxious to alert the medical community. They hoped to publish their findings quickly in the New England Journal of Medicine (NEJM), one of the largest-circulation journals. But the NEJM editors were unwilling to accelerate their several-months-long review and editing process, and in the meantime they couldn’t even guarantee that the article would be published. But if the physicians leaked their findings to the popular press, the journal would unquestionably pull their paper.

But then they thought of a way to get the news out quickly without jeopardizing their chances of being published in the prestigious NEJM. They sent their report on the cluster of five unusual patients to the Centers for Disease Control (which still goes by “CDC,” even though “and Prevention” was later added to its name), for inclusion in the agency’s weekly newsletter, the Morbidity and Mortality Weekly Report (MMWR).


In July 1981, the MMWR ran another AIDS-related report. This one told of 26 cases of Kaposi’s sarcoma (KS) and other opportunistic infections among gay men. It was titled “Kaposi’s Sarcoma and Pneumocystis Pneumonia Among Homosexual Men—New York City and California.”

No one knew what was causing these infections. Some thought “poppers,” a nitrate-based inhalant, were to blame. Although meant for heart patients, the drug was widely abused by gay men in the 1970s and ’80s to enhance sex. Saxon and Gottlieb, however, suspected that an infectious agent—possibly cytomegalovirus, a herpesvirus that is normally harmless in healthy individuals—was to blame. But, Saxon admits, “we didn’t recognize it as blood-borne at first.”

Over the next few years, Saxon became immersed in the AIDS epidemic. (His research specialty was, and still is, B-cell immunity and allergy.) He read every article he could on the disease. In 1983, he started the first AIDS newsletter. He spoke frequently at medical meetings and was interviewed often by the media.

He believes the cause of AIDS might have been harder to find if Japanese researchers hadn’t laid the groundwork in the 1970s by identifying the first human retrovirus, adult T-cell leukemia virus. “If that

U.S. Public Health Service (USPHS) recommends how to prevent AIDS transmission by sexual contact and blood transfusions. CDC adds a fifth risk category: female sex partners of men with AIDS. World Health Organization (WHO) begins global surveillance of AIDS.
hadn’t happened, we would have thought we had the plague,” he says. Instead, within two years after the seminal MMWR report, Dr. Luc Montagnier at the Pasteur Institute in France and Dr. Robert Gallo at the National Institutes of Health in the United States independently discovered that AIDS was caused by a retrovirus. Montagnier called it lymphadenopathy-associated virus (LAV), and Gallo dubbed it human T-cell lymphotropic virus type III (HTLV-III). By 1985, researchers had determined the two were the same, and the virus was renamed human immunodeficiency virus (HIV).

By the early 1990s, Saxon had suspended publication of his AIDS newsletter and returned to his allergy research. He still pays attention to what’s happening in the AIDS field, though. He’s pleased that so many antiviral drugs have been developed to combat AIDS, but he’s surprised that an AIDS vaccine is proving elusive. “The virus is very clever in its ability to shift and hide” from the immune system, he concedes. “It mutates all the time.”

Crusading for acceptance

Dr. C. Everett Koop, Dartmouth College ’37: former U.S. Surgeon General; now a professor of surgery, of community and family medicine, and of psychiatry at Dartmouth Medical School and senior scholar of Dartmouth’s Koop Institute

C. Everett Koop spent most of his career as a pediatric surgeon, so a disease that appeared to affect only gay men was far outside his ken. Nevertheless, when the first MMWR reports came out, he recognized that these unexplained infections spelled trouble. The problem was that he’d been appointed but not yet confirmed as U.S. surgeon general, so he felt powerless to speak out. Even after his confirmation in November of 1981, he had little influence at first over how the Reagan administration communicated to the country about AIDS.

Koop says that in the early 1980s, President Reagan didn’t realize the implications of AIDS. “One thing that was absolutely obvious was that members of the cabinet and members of the domestic policy council kept Reagan and me apart,” Koop contends. “They didn’t keep him informed. It made him look as though he didn’t care, or didn’t know what to do about it, or was a heartless guy—all of which are wrong.”

But other governmental agencies were acting. “Even if people like me are muzzled and not allowed to say what they want to, the momentum of the CDC, NIH, FDA . . . keeps rolling on,” says Koop.

There was momentum in AIDS research, too. “We learned as much about AIDS in six years as we learned about the hepatitis virus in over 40 years,” Koop says. “Largely that was because we had done so much bench science on cancer.”

The effort to encapsulate in only a few words contributions by alumni and faculty to the fight against AIDS resulted in a few passages that don’t fully reflect some faculty members’ current work. Wira heads a National Institutes of Health Program Project Grant designed to increase knowledge of immune protection in the human female reproductive tract and provide information regarding the prevention of local infection in the genital mucosa; such knowledge will be useful in managing sexually transmitted diseases and in understanding heterosexual HIV transmission.

Princess Diana shakes hands with AIDS patients without gloves to show the disease can’t be spread by normal contact.

AIDS is the first disease ever debated on the floor of the UN General Assembly. The body resolves to mobilize the UN against AIDS, under WHO leadership.

WHO declares the first World AIDS Day.

The U.S. bans discrimination against federal workers who are HIV-positive.

U.S. Food and Drug Administration (FDA) approves zidovudine, AZT, the first antiretroviral for the treatment of AIDS.

Entertainer Liberace dies of AIDS.

The AIDS Memorial Quilt is started in San Francisco (it comes to Hanover in 1991).

A summary of Surgeon General Koop’s report, Understanding AIDS, is mailed to every U.S. household.

More celebrities die of AIDS, including choreographer Alvin Ailey and photographer Robert Mapplethorpe.

Congress passes a resolution to create the National Commission on AIDS.

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U.S. NIH establishes the Office of AIDS Research as a separate agency.

The U.S. declares that the first World AIDS Day.

The Americans with Disabilities Act is passed; it prohibits discrimination based on disability, including HIV/AIDS.

Ryan White dies and Congress approves the Ryan White CARE Act to provide community-based AIDS care.

Dr. C. Everett Koop, Dartmouth College ’37: former U.S. Surgeon General

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The CDC reports the possible transmission of HIV to a patient during a dental procedure. The dentist had been diagnosed with AIDS three months before performing the procedure.
In 1986, Koop prepared a report on AIDS that he calls "the most frank report that was ever put in the federal register. I used four words which I thought, talking about AIDS, you couldn’t avoid using... penis and vagina and rectum and condom."

"We couldn’t see the virus, but we could see the footprints of where it had been. That was of great help, because knowing about the virus enabled us to clean the blood supply up.” By 1985, just four years after the first MMWR report, U.S. blood banks were able to screen for HIV.

In 1986, Koop prepared a report on AIDS that he calls "the most frank report that was ever put in the federal register. I used four words which I thought, talking about AIDS, you couldn’t avoid using... penis and vagina and rectum and condom." Back in those days, many people worried that AIDS could be transmitted by cats, mosquitoes, doorknobs, toilet seats, and even casual social contact. "My job as a health educator for the government at that time was not only to explain, 'This is how you get AIDS,' but perhaps even more important, 'This is how you do not get AIDS.'"

Koop made it clear that AIDS was spread by the transmission of specific body fluids—semen and blood. "I went to tremendous lengths" to emphasize that "you didn't get it from kissing a girl goodnight, and you didn't get it from driving a car that an AIDS person had driven," he says. "That was very important because people were being kept out of school because it was thought that they would contaminate other children."

Then in 1988, a flyer titled Understanding AIDS, a summary of Koop's 1986 report on the disease, was mailed to all 107 million U.S. households.

"I did a lot to help educate people," says Koop. "Essentially, what the country needed was a frank, charismatic leader who was not afraid to talk about AIDS." The fact that Koop had come into the Reagan administration as an acknowledged conservative made his forthright approach to AIDS all the more powerful.

When mandatory AIDS testing was proposed in 1987, Koop and other public health officials worried that it would result in widespread discrimination against those who were HIV-positive and might drive people with HIV/AIDS underground, away from help and counseling. AIDS testing has remained voluntary and anonymous. Koop thinks it's time to change that policy, however, so that public health departments can use contact tracing to stem the virus's spread, as they do for other sexually transmitted diseases.

Today, a few months shy of his 90th birthday but still active as senior scholar of the Koop Institute at Dartmouth, Koop continues to be a relentless advocate for public health and health education.

**Reaching around the world**

Dr. C. Fordham von Reyn, DMS '69: now a professor of medicine (infectious disease) at Dartmouth Medical School and chief of the infectious disease section at Dartmouth-Hitchcock Medical Center

In the early 1980s, AIDS was exploding in the nation's cities. But it was also quietly making its
Richard Zuckerman studies the interactions between HIV and herpes simplex virus (HSV) because over half of persons with HIV are also infected with HSV. He also does research to clarify clinically important interventions that may prevent HIV transmission and/or progression.

Way to rural New Hampshire and Vermont, too.

“The earliest patients we saw with AIDS in New Hampshire were gay men who had moved back from urban areas and were dying of the disease, and hemophiliac men who were living locally and had been receiving concentrated blood products from hundreds of donors,” says infectious disease expert Fordham von Reyn. “I saw my first patient in 1983. He came back from New York City almost terminally ill. At this point, the stigma was tremendous. His family, who owned a local business, didn’t want to be taking him out of the house. I made house calls. I didn’t have anything much to offer other than treating complications and symptoms and trying to provide some comfort.

“It was wonderful in the late ’80s when we had the first drug to treat HIV,” von Reyn continues. “But unfortunately we treated people with serial monotherapy—one drug at a time. When one failed, we switched to another, and later realized that this was an ideal recipe for introducing resistance. So when multiple-drug treatment became the standard in the 1990s, then we really saw a tremendous difference in how people did. Patients who were sick in bed, dying, . . . perked up, gained weight, went back to work,” after taking what came to be known as the AIDS “cocktail.” By that time, for patients in the U.S., AIDS was no longer a death sentence but a manageable chronic disease.

Yet no one predicted that AIDS would spread the way it has—that Africa and the Indian subcontinent would see infection rates well into the double digits and that heterosexual men, women, and children would far outnumber gay men in the ranks of the HIV-positive. Today, the typical AIDS patient is a young, married, monogamous woman in Africa. But the disease continues to have social, medical, and economic implications for developed and undeveloped nations alike.

“None of us realized at the beginning that this would become a worldwide pandemic,” says von Reyn. Today, he’s turned over the care of local AIDS patients to colleagues and is attacking the disease on a far broader front. He is one of the leaders of the DARDAR Project, based in the central African nation of Tanzania. The HIV infection rate in Tanzania is 10% in adults and 30% in pregnant women. DARDAR, a collaboration between Dartmouth Medical School and Tanzania’s Muhimbili University College of Health Sciences (MUCHS), includes a clinic for children with HIV/AIDS, a trial for a tuberculosis vaccine (tuberculosis being a common complication of AIDS), and a program to train Tanzanian researchers.

The term DARDAR was drawn from the first three letters of “Dartmouth” and “Dar es Salaam,” the city where MUCHS is located. In addition, the acronym is similar to the Kiswahili word “dada,” which means “sister.” The close relationship between the two institutions—and their commitment to rural New Hampshire and Vermont, too.
to address AIDS together—was broadened six months ago to be a Dartmouth-wide project called the Global Health Initiative. Von Reyn expects to focus on those efforts for some time to come.

Investigating implications
Dr. Andrew Saykin: now a professor of psychiatry and of radiology at Dartmouth Medical School

In 1984, Andrew Saykin was a junior faculty member at the University of Pennsylvania when he was offered the opportunity of a lifetime—to work on a mysterious new disease. Dr. Robert Janssen, a CDC neurologist who had trained at Penn, asked for Saykin’s help in assessing the neurological effects of early-stage AIDS. Late-stage AIDS patients often developed dementia, but “the big question was ‘What about all the people who had been exposed to whatever was causing HIV?’” explains Saykin. “As a recently minted neuropsychologist at Penn, I was in the business of designing cognitive test batteries to try to be sensitive to subtle cognitive dysfunction.”

So Saykin became a consultant to the CDC and had a chance to “go with the CDC team to the International AIDS Conference and present data.” His research up to that point had focused on diseases with “a long research tradition behind them . . . epilepsy, schizophrenia, and Alzheimer’s.” But AIDS represented uncharted territory. “The etiology was just emerging,” he points out. “It was a fatal disease. It was also very poignant in terms of working with these patients. We gave them about a three-hour battery of detailed cognitive tests, tests for anxiety and stress and depression, and so on.”

Saykin was touched by how cooperative and motivated the AIDS patients were.
Tending to teens

Dr. Karen Kramer Hein, DMS ’68: now retired; formerly a professor of pediatrics and epidemiology at Albert Einstein College of Medicine, executive director of the Institute of Medicine, and president of the William T. Grant Foundation

Karen Hein likens the early years of AIDS to a whale-watching expedition. “Everybody’s looking at the tail,” she says, meaning where the epidemic has been evident. “Meanwhile, the ‘whale’ is going under the water—and where it’s going to surface, where it’s heading, is adolescents.”

Hein was savvy about adolescent health issues partly because she had been medical director of a juvenile detention center in New York City in the 1970s. There, she had treated adolescents who had sexually transmitted diseases, were abusing drugs, and were engaging in other risky behaviors. The diseases among her patients at the detention center were “like a beacon for what’s going to become news, or happen in the community on a larger level,” she says. “Long before heroin was known to be an epidemic for young people, we had kids who were using heroin detoxing in our infirmary.”

As soon as researchers determined that AIDS was a sexually transmitted disease, Hein realized that adolescents were at risk. “Part of the rationale for concern,” she explains, “was that if teenagers were getting HIV, they probably look healthy, they probably wouldn’t even know they were sick, and they wouldn’t get sick until they were in their twenties.” But no one listened. “Then, lo and behold, people in their twenties started getting sick.”

In 1987, Hein opened the world’s first comprehensive AIDS program for adolescents. Even by then, some of her colleagues in New York City were skeptical. “They called us the ‘emperor’s new clothes clinic,’” she says. “Then, lo and behold, people in their twenties started getting sick.”

Hein worked tirelessly to build awareness about adolescents. "Long before heroin was known to be an epidemic for young people, we had kids who were using heroin detoxing in our infirmary."

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HIV/AIDS in adolescents. She published abstracts, articles, and book chapters; spoke at numerous professional meetings; and collaborated with the New York City Board of Education to expand AIDS education in the public schools. In 1989, she published an explicit book for teens titled AIDS: Trading Fear for Facts. “We became the ambassadors, or the Johnny and Joanna Appleseeds, for AIDS awareness,” she says.

In 1991, she met basketball player Magic Johnson—shortly after his public announcement that he had AIDS. Hein began counseling Johnson on his AIDS-education activities. Soon, with his star-power behind the effort, “the issue went from being invisible to high visibility,” recalls Hein. She also began training interested teens in how to talk effectively to the media.

But even though awareness of adolescent AIDS was growing, Hein was disheartened to see the familiar issues of denial, stigma, and discrimination play out on the adolescent stage. A few years later, the same issues would surface on the international stage.

Although now retired, Hein continues to be involved as a volunteer in HIV/AIDS initiatives around the world. In countries with effective education and outreach efforts—including condom availability—“HIV rates are plummeting,” she says. But in other countries, “when people die, they don’t say what they died of. So it’s almost like the 1980s all over again.”

Looking ahead
“There was no way of knowing that AIDS would sweep through the world like it did,” says Dartmouth faculty member Ford von Reyn. “But once you began to see that it was occurring by blood transmission, by sexual transmission, and by mother-infant transmission, and once it was recognized how common it was in central Africa, then it was really clear that the world was facing a huge international public-health crisis.”

“I don’t think in our lifetime that AIDS is going to go away,” alumna Karen Hein concludes sadly. “Skipping ahead 100 years, when they look back on our lifetime, . . . I think we’ll be known for a pandemic—and it’s not going to be bird flu.

“I think it’s going to be AIDS.”