America's 40-Year AIDS Journey

By Stephen A. Smith

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Sifting through the remains of a burned house in the sweltering heat, a woman and her husband wonder how the friendly central Florida town of Arcadia came to be so unfriendly. It was the summer of 1987. A few hours earlier this was a family home, buzzing with the boundless energy of four kids and a mom and dad who worked hard to provide for them. Until just a few days ago, life here was simple and easygoing for this family. But today, their home is a charred pile of rubble, the work of an arsonist who would never be caught. As the beleaguered pair look to salvage whatever memories they can, a car speeds by and its passenger shouts, "Get out of our town!"

While the outburst was brief, it spoke volumes about America's 40-year history with HIV.

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In the United States, 1.1 million people are living with HIV/AIDS, including 181,000 (15.9 percent) who are unaware. Since 1981, 658,000 have died, and there are now 50,000 new HIV diagnoses and 15,000-17,000 deaths from AIDS each year.

It is widely believed that HIV originated around 1920 in Kinshasa, in the Democratic Republic of Congo, when HIV crossed species from chimpanzees to humans. We do not know how many people have been infected with HIV or developed AIDS, as transmission was not accompanied by noticeable signs or symptoms, and HIV was unknown until the 1980s.

While sporadic cases of AIDS were documented prior to 1970, available data suggests that the current epidemic started in the mid-to-late 1970s and that by 1980, HIV may have already spread to five continents (North America, South America, Europe, Africa and Australia) and infected 100,000 to 300,000 people.

In 1981, cases of a rare lung infection called *Pneumocystis carinii pneumonia (PCP)* were found in five young, previously healthy gay men in Los Angeles. At the same time, there were reports of groups of men in New York and California with an unusually aggressive cancer named *Kaposi sarcoma*. The first signs of Kaposi are usually cancerous lesions on the skin that are purple, red or brown, commonly located on the feet, legs and face. These tumors can spread to the lymph nodes and lungs, and their emergence indicates a compromised immune system.

In December 1981, the first cases of PCP were reported in people who injected drugs. By the end of the year, there were 270 reported cases of severe immune deficiency among gay men, and 121 of them had died.

In June 1982, a group of cases among gay men in southern California suggested that the cause of the immune deficiency was sexual and the syndrome was initially called gay-related immune

deficiency (GRID). Later that month the disease was reported in hemophiliacs and Haitians, leading many to believe it had originated in Haiti.

In September 1982, the United States Centers for Disease Control and Prevention (CDC) used the term 'AIDS' (acquired immune deficiency syndrome) for the first time, describing it as "a disease at least moderately predictive of a defect in cell mediated immunity, occurring in a person with no known case for diminished resistance to that disease." AIDS cases were increasingly reported in Europe, Africa and the United States.

In early 1983, the CDC reported that most cases of AIDS had been found among homosexual men, intravenous drug users, Haitians and hemophiliacs, suggesting that AIDS may be caused by an infectious agent that is sexually transmitted or passed through exposure to blood products. AIDS was reported among the female partners of men who had the disease, suggesting it could be passed on via heterosexual sex. By the end of that year, the CDC published their first set of recommended precautions for healthcare workers to prevent "AIDS transmission," and the World Health Organization (WHO) held its first meeting to assess the global AIDS situation and began international surveillance.

As 1983 drew to a close, the number of AIDS cases in the United States had risen to 3,064 and of this number, 1,292 – over 42 percent – had died.

Researchers at the Pasteur Institute in France isolated and identified the HIV virus. Originally called Lymphadenopathy-Associated Virus (or LAV), the virus was confirmed as the cause of AIDS. Meanwhile, in the United States, scientists at the National Cancer Institute isolated the same virus and called it HTLV-III.

In a joint conference in April 1984, the two organizations announced that LAV and HTLV-III were identical, and the likely cause of AIDS. A blood test was created to screen for the virus with the hope that a vaccine could be developed.

In July, the CDC stated that avoiding injecting drug use and sharing needles "should also be effective in preventing transmission of the virus." In October, bathhouses and private sex clubs in San Francisco were closed due to high-risk sexual activity. New York and Los Angeles followed suit within a year.

By the end of 1984, there had been 7,699 AIDS cases and 3,665 AIDS deaths reported in the United States. With the number of cases and the death rate rising, fear, confusion and hopelessness spread like a cruel wildfire through the gay communities of New York, San Francisco and other large cities throughout the United States.

Everyone was afraid

In the 1980s, interior designer Ed Bryce was "living the dream" in New York City, drinking in all the city had to offer – restaurants and nightlife, shopping and Broadway shows. He said he was "on top of the world" when he met a man named Charles, and the couple began a monogamous relationship. Then along came AIDS. They called it "the gay cancer" and it hit New York City hard.

"Everyone was afraid," Ed recalled. "The gay men were afraid because they didn't know if they had it or how they could get it. The straight men were afraid because they didn't know if they were

going to [get it when they] touch somebody or breathe in some germs. It was a mess. Charles and I thought it was time to get out of Dodge."

Attempting to escape the AIDS epidemic, Charles and Ed left New York and relocated to Sarasota, Florida, in 1982. Charles passed away of AIDS just 10 months later. Ed was tested for HIV and found that he too had AIDS, with a T-cell count of less than 200.

Sad, angry, confused and alone, Ed wasn't sure what to do next. But the woman who conducted his HIV test gave him the name and phone number of someone who would change his life – Sister Frances Nevolo of the Catholic Diocese of Venice.

"She turned out to be my angel," declared Ed, describing how Sister Frances referred him to Dr. Jeffrey Stall and his recently-established Comprehensive Care Clinic in Sarasota. Under Dr. Stall's care, Ed began to "feel better and better."

In 1992, the new Comprehensive Care Center opened at 150 S. East Avenue in Sarasota. Ed said, "Now we had a place we could call 'Our Clinic.' If you got sick, you could go to the clinic and there would be somebody there to take care of you. And that was huge!"

Shortly after the Clinic opened, Susan Terry, president of Community AIDS Network (the organization that would later become CAN Community Health) and co-founder of the clinic, gave birth to a baby boy. As Ed recalled, "Nobody would touch us if they knew we had AIDS, but knowing this – guess what? She let us hold Jimmy. Oh, my God, what that meant! People on the street wouldn't shake my hand, but this woman could let me hold her baby. It was remarkable then, and it still is remarkable to me now."

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- Ed Bryce

Get out of our town: Society's battle with the disease… and itself

From high-profile cases of families fighting in court for the right of their children to attend school, to the social stigma that keeps some segments of our society hiding in the shadows, AIDS-related discrimination has been a grim reality from the beginning.

Socially conservative and religious communities equate HIV with immoral behavior. This stigma persists even today, and it keeps many young people, particularly in impoverished communities in the southern United States, from seeking treatment.

In the 1980s, a few high-profile cases of AIDS-related discrimination focused national media attention on the emerging AIDS epidemic and how it affected individuals, families and communities. Countless others have gone unrecognized but rendered no less anguish on the families affected.

In 1985, 13-year-old Ryan White of Kokomo, Indiana, was diagnosed with AIDS following a blood transfusion in December 1984. Doctors gave Ryan just six months to live, and he was banned from attending middle school. A protracted legal battle ensued and White became a "poster child" for HIV/AIDS.

Along with his mother, Jeanne White Ginder, Ryan lobbied for his right to attend school, gaining national attention and becoming the face of public education about his disease. Surprising his doctors, Ryan outlived their projections by five years. He died in April 1990, one month before his high school graduation and only months before Congress passed the legislation bearing his name: The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, the largest federally-funded program for people with HIV/AIDS.

In 1986, Attorney Geoffrey Bowers was fired from the Philadelphia law firm, Baker & McKenzie, after Kaposi's sarcoma lesions appeared on his face. He successfully sued the firm, and his battle became the inspiration for the 1993 film *Philadelphia*, which starred Tom Hanks.

In the Central Florida town of Arcadia, the family of Ricky, Robert and Randy Ray, three hemophiliac brothers who, like Ryan White, contracted the HIV virus through blood transfusions, were barred from attending public school. In August 1987, the Rays won their federal court case against the DeSoto County school board. A week later, the family's home was doused with gasoline and burned to the ground. At a news conference with the parents, someone shouted out, "Next time you won't be so lucky." The family fled to nearby Sarasota.

A New York Times story dated August 30, 1987 describes how Lauri Rummer, a cousin of the boys' father, was sorting through the remains of the house when a car sped by and a passenger shouted, ''Get out of Arcadia! Get out of town, Rays!'' Lauri and her husband, Loni, said they had been able to salvage ''crystals, pictures and knick-knacks'' from the gutted home. The fire was ruled a case of arson, and never solved.

The AIDS Memorial Quilt: Something beautiful, useful and warm

In 1985 Cleve Jones, co-founder of the San Francisco AIDS Foundation, and his colleagues attended a candlelight vigil marking the assassinations of San Francisco Mayor George Moscone and Supervisor Harvey Milk. To Jones and his friends, the montage of placards they'd taped to the front of the San Francisco Federal Building commemorating loved ones lost to AIDS resembled an enormous patchwork quilt.

Jones created the first panel of the AIDS Memorial Quilt in memory of his friend Marvin Feldman. Envisioning the Quilt as a tool to reveal the humanity behind the AIDS death toll, Jones said that quilts evoke images of pioneer women making camp by their Conestoga wagons or slaves hoarding scraps of fabric from their masters' houses – castoffs of different colors and textures that would be sewn together to create something beautiful, useful and warm.

Public response was immediate and the grassroots project grew exponentially. Bereaved families, spouses and friends were encouraged to share their grief by creating quilt panels. Measuring 3 feet by 6 feet (the approximate size of a grave) the panels paid tribute to individuals or groups of people who had died of AIDS. Panels would then be assembled into 12-foot-square blocks.

In 1987 Jones teamed up with Mike Smith and several others to organize the NAMES Project Foundation. By the time the AIDS Memorial Quilt was first shown in October 1987 at the National Mall in Washington, DC, it included 1,920 panels and covered an area larger than a football field.

By 1992, when the number of AIDS-related deaths in the United States had passed 250,000, the Quilt comprised panels from every state and 28 countries. By October 1996, AIDS deaths surpassed 580,000 and the Quilt covered the entire breadth of the National Mall. This was the last time the Quilt was displayed in its entirety.

More than 14 million people have visited the Quilt at thousands of displays worldwide. Through this activity, the NAMES Project Foundation has raised over $3 million for AIDS service organizations throughout North America.

Today, the Quilt is an epic, 54-ton tapestry with more than 48,000 panels dedicated to more than 100,000 individuals. It remains the largest community art project in history – a living memorial and an important education tool. In 2019, the National AIDS Memorial became the permanent caretaker and steward of the Quilt, returning it to San Francisco where its story began.

> "Today we have borne in our arms and on our shoulders a new monument to our nation's capital. It is not made of granite or steel and was not built by stonecutters and engineers. Our monument is sewn of fabric and thread, and was created in homes across America and wherever friends and families gathered to remember their loved ones lost to AIDS."
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> Cleve Jones, The NAMES Project Foundation
> October 1992

Science steps up

Following the 1987 approval by the US Food and Drug Administration (FDA) of the antiretroviral medication **zidovudine** (**ZDV**), also known as **azidothymidine** (**AZT**), new drugs and combination drug therapies began emerging, gaining considerable momentum in the mid-1990s. By 2014, there were more than 30 drugs available to suppress HIV and delay the virus' progression to AIDS. A partial list includes:

- Fuzeon® (enfuvirtide, also known as T-20) was approved by the FDA for use in combination with other anti-HIV medications in 2003. Fuzeon was the first fusion inhibitor, also known as an entry inhibitor.

- The FDA approved OraQuick in 2004, the first oral rapid HIV test, producing results in 20 minutes with 99 percent accuracy. In 2012, the FDA approved a new version for in-home use that provides results in 20 to 40 minutes.
- Complera®, the second all-in-one combination tablet that expanded treatment options for people living with HIV, was approved by the FDA in 2011.
- In 2012, Truvada® was approved by the FDA for prevention of HIV in high-risk individuals. Since 2014, the drug has been used for both Post-Exposure Prophylaxis (PEP) and Pre-Exposure Prophylaxis (PrEP).

Preventing HIV infection

A couple of recently approved drug protocols can actually prevent HIV infection. "PrEP" (pre-exposure prophylaxis) is a protocol aimed at those who may be at-risk for HIV. Participants take a vaccine aimed at preventing them from getting HIV from sex or injection drug use.

According to the U.S. Centers for Disease Prevention and Control (CDC), PrEP has been shown to be highly effective for preventing HIV. PrEP reduces the risk of getting HIV from sex by about 99 percent when taken as prescribed. There is less information about how effective PrEP is among people who inject drugs, but estimates are that PrEP reduces their risk of getting HIV by at least 74 percent when it is taken as prescribed.

Research trials offer new hope

Clinical research studies help public health officials to better understand HIV. They also assist in the discovery of promising new tools to prevent HIV infection, including a vaccine, and contribute to the development of new and more effective treatment strategies.

There are 84 clinical studies related to Acquired Immunodeficiency Syndrome that are currently recruiting participants, according to the National Institutes of Health's National Institute of Allergy and Infectious Diseases. More information can be found on NIH's ClinicalTrials.gov website.

Federal programs make care affordable

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, enacted by the U.S. Congress in August 1990, is the largest federally funded program in the United States for people living with HIV/AIDS. Through contingency grants to states, this act made federal funding available for low-income, uninsured and under-insured people to be treated with the chemotherapeutic drug AZT.

Administered by the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB), the Ryan White HIV/AIDS Program provides a comprehensive system of HIV primary medical care, essential support services and medications for low-income people with HIV. The program funds grants to states, cities, counties and local community-based organizations to provide care and treatment services to people with HIV, to improve health outcomes and reduce HIV transmission among hard-to-reach populations.

More than half of people with diagnosed HIV in the United States receive services through the Ryan White HIV/AIDS Program each year. For fiscal year 2021, federal funding for the program totals $2.4 billion.

Created in 1992, The 340B Drug Pricing Program is a US federal government program that allows qualifying providers – generally hospitals, specialty clinics and their associated outpatient facilities (also referred to as "covered entities") serving uninsured and low-income patients in rural communities – to purchase outpatient drugs from manufacturers at discounted prices. The intent of the program is to allow providers to stretch scarce federal resources as far as possible, reaching more eligible patients and providing more comprehensive services. Manufacturers participating in Medicaid agree to provide outpatient drugs to covered entities at significantly reduced prices. As of October 2017, there were 12,722 covered entities participating in the program.

Delivering vital, community-based care

Among the organizations dedicated to the treatment, care, and continual wellness of people living with HIV, hepatitis C, and other sexually transmitted infections is CAN Community Health (CAN).

CAN is a nonprofit community-based organization established in 1991 with clinics/partnerships in Florida, five other states and Puerto Rico. They provide medical, pharmacy, dental, case management, mental health, and comprehensive prevention services, such as nPEP, PrEP, and Prevention-with-Positives. CAN also provides screening and treatment for hepatitis C and STDs, as well as transgender health services.

The organization's footprint has expanded from a single location in 1992 (the clinic described by Ed Bryce) to 36 sites, with more than 100 providers caring for more than 20,000 individuals through Ryan White grants, STD prevention funding, and the 340B Federal Drug Discount Program. Medical mobile units extend care to individuals in rural communities.

Health Disparities and HIV

If we are going to end the HIV epidemic in the United States, it is essential to understand why HIV has a disproportionate impact on certain groups over others.

We need to identify the factors that drive the health disparities we see at the local, state and national levels. The Centers for Disease Control and Prevention (CDC) defines health disparities as "differences in the incidence, prevalence, and mortality of a disease and the related adverse health conditions that exist among specific population groups. These groups may be characterized by gender, age, race or ethnicity, education, income, social class, disability, geographic location, or sexual orientation."

HIV-related health disparities are significant among racial and ethnic minorities. For example, in 2018, Black Americans represented only 13 percent of the U.S. population, but 41 percent of all people living with HIV. Black Americans also experience social determinants of health (SDOH) that

often lead to poorer health outcomes. According to the U.S. Department of Health & Human Services, examples of SDOH include:

- Safe housing, transportation, and neighborhoods
- Racism, discrimination, and violence
- Education, job opportunities, and income
- Access to nutritious foods and physical activity opportunities
- Polluted air and water
- Language and literacy skills

Cultural practices can also pose barriers to accessing HIV education and care. In some cultures, it is a taboo to discuss illness, especially when related to sex. According to the CDC, cultural practices can contribute to stigmatized beliefs about HIV, fewer instances of seeking essential HIV medical care, a significant underreporting of HIV cases, and an inequitable allocation of resources.

Two-thirds of all new HIV diagnoses in 2018 were among gay and bisexual men, despite this group comprising only two percent of the U.S. population. In the LGBTQ community, HIV stigma has persisted since the epidemic first began. Confusion about how the virus spread made it easy to blame the LGBTQ community, which reinforced existing negative bias and led to violence against individuals and groups.

Discrimination has bled into the workplace, the justice system and health care centers, complicating people's efforts to live as healthy and economically stable individuals. Although newer health care policies (such as the Affordable Care Act and same-sex marriage legalization) have reduced some barriers to accessing health insurance, many LGBTQ individuals struggle to pay for medical treatment.

A new national plan

In 2019 the United States Department of Health & Human Services (HHS) introduced its national plan, *Ending the HIV Epidemic: A Plan for America (EHE).* The HHS describes this ten-year federal initiative as a once-in-a-generation opportunity to end the HIV epidemic. Its goal is to reduce new HIV infections by 75 percent by 2025, and by 90 percent – to less than 3,000 per year – by 2030.

The initiative is leveraging critical scientific advances in HIV prevention, diagnosis, treatment, and care by coordinating the programs, resources and infrastructure of many HHS agencies and offices:

- Centers for Disease Control and Prevention (CDC)
- Health Resources and Services Administration (HRSA)
- Indian Health Service (IHS)
- National Institutes of Health (NIH)
- Office of the HHS Assistant Secretary for Health (OASH)
- Substance Abuse and Mental Health Services Administration (SAMHSA)

The plan will focus on four key strategies:

- **Diagnose** all people with HIV as early as possible.
- **Treat** people with HIV rapidly and effectively to reach sustained viral suppression.
- **Prevent** new HIV transmissions by using proven interventions, including pre-exposure prophylaxis (PrEP) and syringe services programs (SSPs).
- **Respond** quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them.

The first five-year phase of the EHE initiative will focus on 57 "priority jurisdictions" where more than 50 percent of new HIV diagnoses occurred in 2016 and 2017. This group includes 48 counties across the United States; Washington, DC; San Juan, Puerto Rico; and seven states (Alabama, Arkansas, Kentucky, Mississippi, Missouri, Oklahoma, and South Carolina) with a disproportionate occurrence of HIV in rural areas.

In Phase II, efforts will expand more widely across the nation to reduce new infections by 90 percent by 2030, 50 years after the HIV epidemic began in the United States.

In Phase III, intensive case management will be implemented to maintain the number of new infections at fewer than 3,000 per year.

Ending the HIV epidemic

The story of HIV in America continues to be a heartbreaking one. With new and continuing research, advancements in treatment, compassion and common sense in public policy, and the generous support of nonprofits by private and institutional donors, America's HIV epidemic can be brought to a close.

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EDITOR'S NOTES AND RESOURCES:

Snapshot: AIDS in the United States

HIV remains a persistent problem in the United States. According to the Centers for Disease Control and Prevention (CDC), from 2018 to 2022, HIV infections decreased in the United States by 12% overall. In 2022, the South accounted for nearly half (49%) of the nation's 31,800 estimated new HIV infections, and Florida ranks as one of the highest states in the nation for the number of people living with AIDS. Learn more about HIV in the United States by visiting the CDC website.

The AIDSvu Map

AIDSvu is an interactive, online mapping tool that can help you visualize the HIV epidemic's impact on communities across the United States. The site uses data from the CDC, local health departments and other reliable sources.