



**THE FIGHT
AGAINST AIDS
1981-2014**

A PITTSBURGH STORY

ROOTS

The Jewish Healthcare Foundation (JHF) is a public charity that offers a unique blend of research, education, grantmaking, and program management to advance the quality of clinical care and health of populations, with a focus on improving the quality, efficiency, and safety of healthcare. JHF and its two operating arms, the Pittsburgh Regional Health Initiative and Health Careers Futures (HCF) are located in Pittsburgh, Pennsylvania, and serve a national and global audience. JHF is also a founding member of the Network for Regional Healthcare Improvement (NRHI). For more information, visit www.jhf.org.

ROOTS publications explore issues central to the advancement of healthcare quality and value. Underlying our goal in preparing this issue of ROOTS is to inform our readers of the progress we have made in the U.S. with the transition of AIDS from a death sentence to a chronic disease. Along the way, there were heroes and activists whose commitments should be recognized. As a nation we learned a lot about how to coalesce around a lethal viral threat. Like some other foundations, the Jewish Healthcare Foundation stepped forward to advocate for research discovery, to care for afflicted individuals and their families, and to educate the community on the public health threat. We would like to recapture that journey for the lessons we learned and for an opportunity to salute the good people we have worked with along the way.

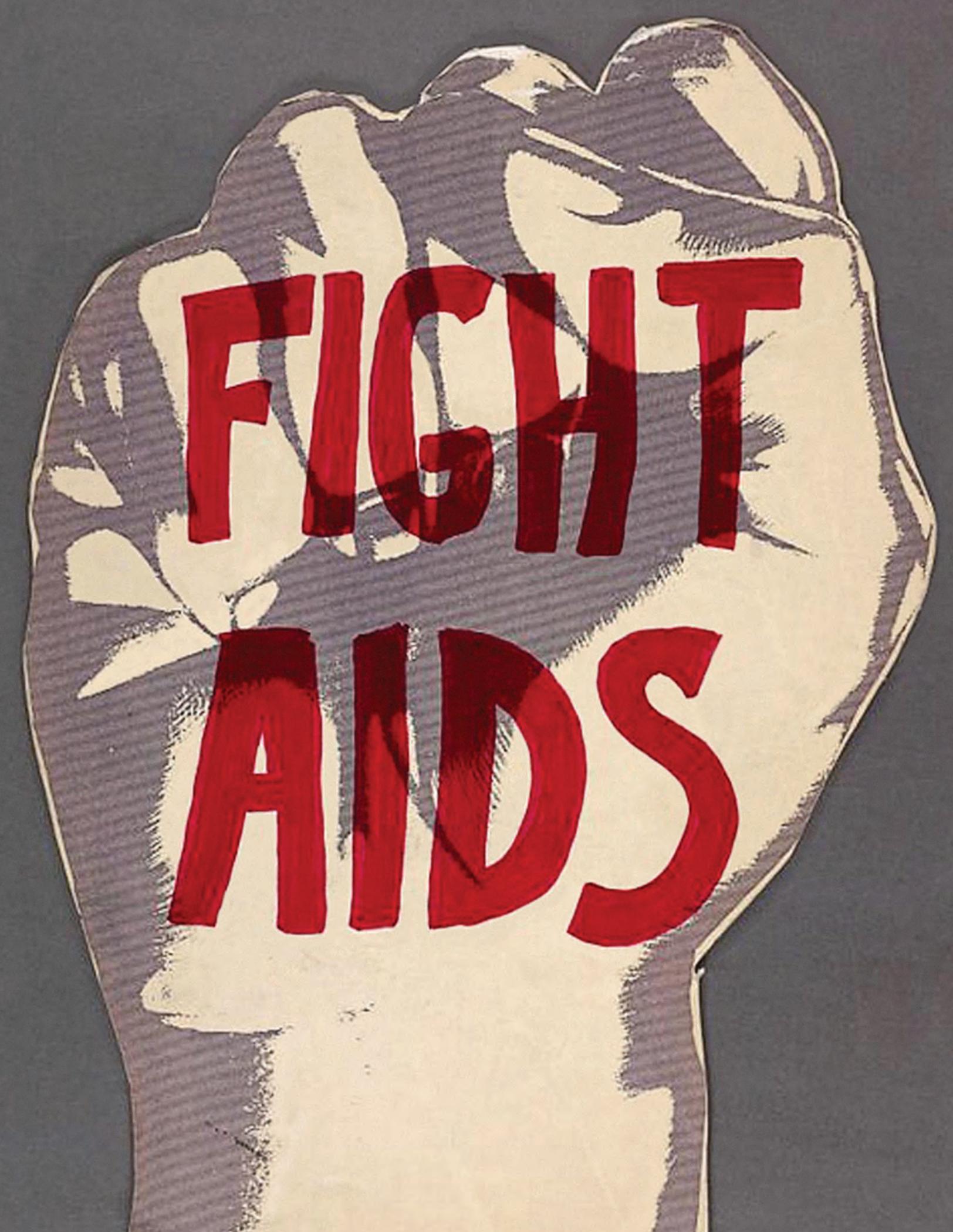
The job isn't "done." People don't have to die of AIDS anymore, yet they still do. There is still a high percentage of persons with HIV who are never linked to care or drop out of care. There are unresolved international issues. But JHF teams are currently breaking ground statewide on new initiatives through our role as fiscal agent for federal Ryan White and Housing and Urban Development funds in Southwestern Pennsylvania, and special grant funding. We would like to share our successes and learnings as we set some strategic priorities for the future.

DEDICATION

We at the Jewish Healthcare Foundation dedicate this Roots to Kerry Stoner, Randy Forrester, Bruce Dixon, and the other early heroes in our region mentioned in this report who are no longer with us.

THE FIGHT AGAINST AIDS 1981-2014: A Pittsburgh Story

Foreword	1
The Epidemic 1981-1999	5
Emerging Anatomy of HIV	5
Early National Initiatives	8
Pittsburgh's Early Response	9
Philanthropy Responds: Funders Concerned About AIDS	16
Jewish Healthcare Foundation: Fiscal Agency 1992-2000	19
The Shift 2000 - Present	23
The Changing Face of HIV	23
Jewish Healthcare Foundation: Fiscal Agency 2001-2014	25
How the World Has Changed: Reflections on the Epidemic's Impact	41
Appendices	46
Biographical Sketches of Interviewees	46
Organizations Funded via the Jewish Healthcare Foundation	51
Endnotes	54



FIGHT

AIDS

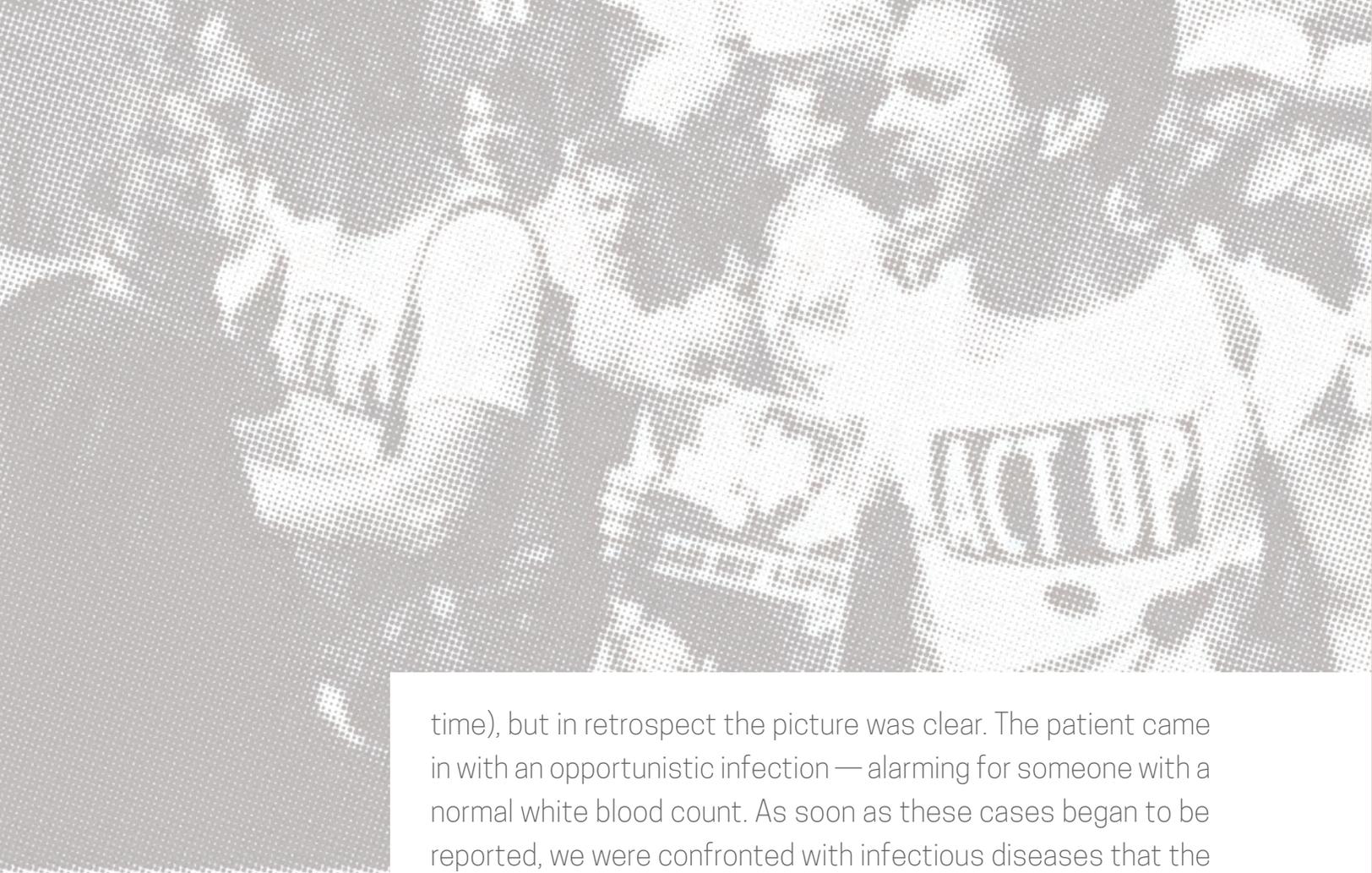


FOREWORD

The predecessor virus of today’s human immunodeficiency virus (HIV) is believed to have emerged as early as 1910. For decades, significant human-to-human transmission quietly awaited the support of later 20th century trends: widespread international travel and colonialization, the sexual revolution, the spread of prostitution — and perhaps even public health practices, like mass immunization campaigns via single-use syringes. As if from nowhere, what would later be known as HIV, and the condition it caused — acquired immunodeficiency syndrome or AIDS — emerged as a major public health concern in the United States in the 1980s.

The Centers for Disease Control and Prevention (CDC) published its first report on the nascent epidemic in 1981¹, describing *pneumocystis carinii pneumonia* (PCP) — a rare infection — in five young, previously healthy gay men. This report was followed by others — each documenting unusual clusters of extremely rare opportunistic infections, first in gay men and later in those with hemophilia and in IV drug users.

The Pittsburgh area saw its first cases in 1982–83. Recalling his first patient, Keith Kanel, MD, an internist who would later become a practitioner for AIDS patients, remarked: “We never confirmed that the patient had HIV (there was no blood test at the



time), but in retrospect the picture was clear. The patient came in with an opportunistic infection — alarming for someone with a normal white blood count. As soon as these cases began to be reported, we were confronted with infectious diseases that the average practicing physician had never seen.”

Within a year of the first CDC report, the gay community in hard-hit cities like San Francisco and New York began to respond in ways that would forever change the face of public health, health education, and health communication.

This ROOTS represents an opportunity to reflect on one community’s evolving response to the HIV epidemic. In the Pittsburgh region, the prevalence of HIV/AIDS was, and continues to be, less than in larger cities; nevertheless, we have lost too many of our family members, friends, neighbors, acquaintances, and fellow citizens. This then is our story.

This edition of ROOTS introduces some of the remarkable people who fashioned both the national and our community’s responses to the epidemic in the 1980s and beyond. It describes how the organizations they founded resisted social prejudice



A MODERN EPIDEMIC

Since the early years of the epidemic, almost 75 million people worldwide have been infected with HIV; half have died. Today just over 35 million people are estimated to be living with HIV, although new medications have contributed to a continuously increasing life expectancy. Sub-Saharan Africa continues to be most seriously affected, accounting for nearly three-quarters of all those living with HIV worldwide.

In the United States, 1.7 million people have been infected with HIV; more than 580,000 have died. New HIV diagnoses remain at around 50,000 per year. Currently, the CDC estimates that 1.1 million people (age 13+) are living with HIV.

Sources: World Health Organization; CDC, Kaiser Family Foundation

and fear to care for those living with the pernicious virus. They embraced the dying and attended funeral after funeral, even before the virus had been discovered and modes of transmission revealed.

This is also the story of the Jewish Healthcare Foundation as it took on the role of fiscal agent in 1992 for funding from the federal Ryan White CARE Act and the HOPWA (Housing and Urban Development — Housing Opportunities for Persons with AIDS) programs. As fiscal agent, JHF's role has evolved as new treatments transformed HIV — and with it the needs of those living with HIV— from a series of acute infectious diseases to a manageable, chronic illness.

Despite such changing needs, the Foundation has always made its overarching responsibility to ensure the prevention of HIV, as well as the integrity and quality of the safety net for people living with HIV in western Pennsylvania.

THE EPIDEMIC



1981–1999

EMERGING ANATOMY OF HIV

At the Centers for Disease Control and Prevention (CDC), Ward Cates Jr., MD, who had just arrived to head the CDC's STD/HIV prevention efforts — understood from the CDC's first 1981 publication that this new disease was different from previous epidemics: "We recognized it within the public health and international community, but no one in the U.S., particularly among heterosexuals, took it seriously."

Even in 1988, *Cosmopolitan* magazine reassured women that, "There is almost no danger of contracting AIDS through ordinary sexual intercourse."¹ Their reassurance extended even to women who were the partners of IV drug users.

From the early years of the epidemic, it was clear that the problem wasn't confined to the U.S. or to the gay population. In Africa, says Cates, "We started seeing waves of heterosexuals dying of the so-called slim disease, as it was known at the time. I remember my first trip to Kampala, Uganda — the main industry was coffin-making. And we had no treatment."

"Anyone who has the least ability to look into the future can already see the potential for this disease to be much worse than anything mankind has seen before."

— WARD CATES JR., MD, 1985

Although the CDC still hadn't identified the illness in 1982, it published precautions for healthcare professions. Remembers Cates, "We knew we were in trouble. We thought we were dealing with something that was transmissible. Through a variety of quick epidemiological studies, we had identified routes of transmission, and based on those routes of transmission came up with recommendations that would help prevent that condition from spreading — whether it was person-to-person (and it eventually became obvious that it was) or whether it was a toxic agent, we were covering all bases." But in 1985, after it emerged that the virus attacked immune T-cells, Cates and others knew "just looking at the biology, that a vaccine was going to be difficult."

Keith Kanel, MD, on the frontline at the time in a Pittsburgh hospital recalls that, "What saved us were the older physicians. There were four or five diseases that were really

important, including *pneumocystis carinii pneumonia*, *toxoplasmosis*, *cytomegalovirus*, and *atypical tuberculosis*. Most of us had never seen advanced *tuberculosis* in the U.S., let alone *atypical tuberculosis*. So there were all of these unfamiliar infections and our labs had to retool to offer testing for the new infections. Also our infectious disease specialists had to research how to treat these infections. In each hospital that dealt with AIDS, there were one or two people who became the experts. And they were almost always infectious disease specialists. This is very important because in the 1980s and 1990s HIV/AIDS was almost entirely an infectious disease concern.”

Observed Kanel, the older internists also reminded “the younger docs to not only look at this as a scientifically interesting disease. They reminded us to try to understand its impact on people’s lives and to counsel the sexual partners of infected people to observe precautions — even before transmission modes were known.”

In 1987, the public sector finally began to respond. The Food and Drug Administration (FDA) approved AZT, an antiretroviral and the first AIDS medication (which slowed disease progression for a time). A year later, the CDC widely distributed a brochure entitled, “*Understanding AIDS*.” Also in 1988, health departments would engage in the first needle exchange programs as the disease spread to IV drugs users. Only in 1990, with the passage of the Ryan White CARE Act (named for an Indiana teenager with hemophilia who died from AIDS contracted from blood products), did the federal government begin to provide systematic support for the network of primarily volunteer-driven community-based organizations that sprang up all over the country. By then, more than 120,000 people had died of AIDS.

Reflecting on reasons for the slow response of the government, Ward Cates noted, “There was a period of time in the early years when there was a real discrepancy between those of us who were charting the course epidemiologically — knowing, for example, that condom use was highly likely to be protective — and those in the higher level political administration who were reluctant to even mention sexual transmission or acknowledge MSM [men who have sex with men] spread, or acknowledge the possibility of heterosexual spread. They became very cautious about taking steps in the early years.”

“We’re forced to deal with this unbelievable circumstance of a community that in addition to being hated and under attack is now forced alone to try to figure how to deal with this extraordinary medical disaster.”

— PAUL BONEBERG, IN THE PBS FILM, *WE WERE HERE*

When those with hemophilia began to be infected, there was panic over the blood supply. In fact, the first major U.S. prevention effort was screening the blood supply. Reflects Cates, “When you look back on it, I suppose this was an important step in gaining support for any HIV prevention effort, but from the lens of a public health practitioner, when we had such limited funds, putting monies into the blood supply when it would affect so few cases was hard. We needed condom campaigns. We needed targeted education to the highest risk groups. At any rate it took a while for that message to get through and it took a new administration — the first Bush administration and then the Clinton administration — to really get things going.”



In 1987, six gay activists in New York formed the Silence = Death Project and began plastering posters around the city featuring a pink triangle on a black background. A short time later, several of them were at the evening event when Larry Kramer spoke, which motivated the community of people to found ACT UP.

EARLY NATIONAL INITIATIVES

A number of reports and articles trying to make sense of what was already clearly a crisis in the gay community were published in 1981 — and the CDC’s June report on a strange cluster of a rare form of pneumonia was not even the first. Lawrence D. Mass, MD, the medical writer for an influential New York gay newspaper called *The Native*, wrote the first article, although the experts he interviewed concluded that disease rumors were “largely unfounded.” But outbreaks of a highly unusual cancer (Kaposi’s sarcoma) and a rising number of deaths were by then beginning to alarm the gay community (by 1981, there had already been 159 deaths in the U.S.²). In July, *The New York Times* ran an article entitled, “Rare Cancer Seen in 41 Homosexuals.” In December, *Time*, *Newsweek* magazine, and *Good Morning America* each also ran significant stories.

In 1981, the fact that a public health crisis was in the making — one that would ultimately claim the lives of over half a million Americans — from all communities and all walks of life — was already clear in New York City and San Francisco. Hamstrung by public anxiety, fear, and prejudice,³ it would take more than six years for the public sector to respond in significant ways. So the gay community responded to the epidemic on its own:

1. Building Community-Based Organizations. In August 1981, Larry Kramer — a playwright and prominent activist in the gay community then (and now) — called for a meeting in his New York City home. Among the 80 attendees, a core group of six formed the Gay Men’s Health Crisis (GMHC) in January 1982.⁴ GMHC provided mostly volunteer-led crisis counseling, legal aid, a buddy system, and social workers as part of an organization that today serves nearly 9,000 people affected by HIV and AIDS. Within two years, GMHC was already reaching out to new high risk groups — heterosexual Haitians and those with hemophilia.

2. Providing Health Education. In May 1983, Michael Callen privately published the nation’s first pamphlet on safe sex and condom use, *How to Have Sex in an Epidemic*.

3. Raising Funds and Awareness.

- In May 1985 the GMHC organized the first *AIDS Walk*, held in New York City, which raised more than \$700,000.
- In 1987, Larry Kramer went on to found the *AIDS Coalition to Unleash Power* (ACT UP). ACT UP was a protest organization aimed at forcing public support in confronting the AIDS epidemic by increasing public awareness of the disease and the human beings struggling with infection. In ACT UP’s first action, the FDA commissioner was symbolically chained to his desk — and then burned in effigy — to protest the agency’s slow speed in approving AIDS drugs. Two years later, ACT UP infiltrated the New York Stock Exchange, unfurling a banner that urged traders to sell the company producing AZT, until prices were lowered to below the then \$12,000 / year. Both actions ultimately led to both policy and price changes.

4. Driving a National Research Agenda: ACT UP activists demonstrated against the delays and red tape surrounding approval of AIDS treatment drugs, especially via its Treatment and Data Committee. Activists became experts on the growing AIDS scientific literature and planned some of the group’s noteworthy demonstrations (at the FDA in 1988, and at the National Institutes of Health (NIH) in 1990) which contributed to a shift in national priorities in favor of streamlined testing and approval of AIDS drugs.

ACT UP member Mark Harrington, who wrote and edited three editions of the National AIDS Treatment Research Agenda (1989–91), later became a cofounder of the Treatment Action Group (TAG), an independent research organization aimed at improving treatment and, ultimately, finding a cure for AIDS. TAG’s influential papers led to legislation that strengthened the NIH Office of AIDS Research in June 1993. The organization, which Harrington still heads, continues its work today.

PITTSBURGH’S EARLY RESPONSE

In Pittsburgh Jim Huggins, PhD, first heard of a newly-discovered disease killing twenty and thirty-somethings on the nightly news. No one knew how it spread, and there was no test to confirm whether a person was infected. It blindsided T-cells — the immune system’s defensive line — and left people vulnerable to opportunistic infections and malignancies. At first, most reported cases were in big cities such as New York, San Francisco, Los Angeles, and Chicago. But then, Huggins began seeing its devastation first-hand in Pittsburgh.

Huggins had co-founded the PERSAD Center with his partner, Randy Forrester, in 1972. It was the country’s second licensed counseling center dedicated to serving the LGBT community. “Homosexuality was still considered a mental illness in mental health circles,” Huggins notes. “So if you went to a therapist, the goal was to ‘cure’ you of being gay instead of helping you to adjust to your minority status and the discrimination and prejudice that you may have experienced.”

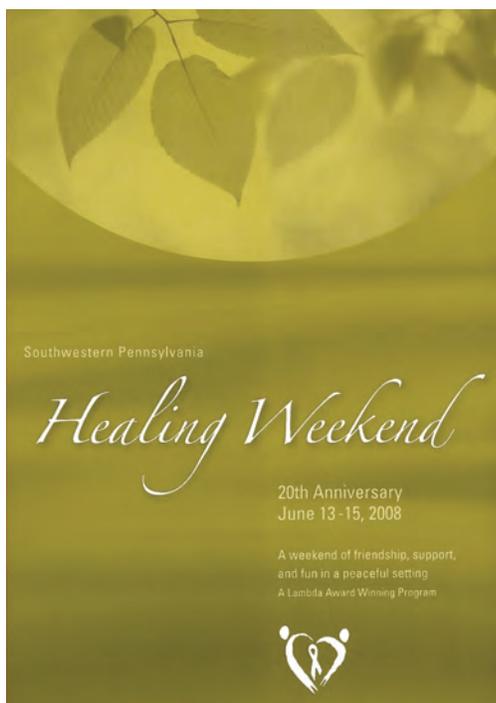
In the early 1980s, more of PERSAD’s clients showed up gravely ill. And then they started dying.

“We saw people infected with certain kinds of pneumonia and Kaposi’s sarcoma, which caused these blue-black lesions on your torso, face, and arms,” Huggins recalls. “There was also wasting syndrome — people got thinner and thinner until they looked emaciated. As soon as we realized the disease was here in Pittsburgh, we broadened our basic mission of mental health services to support those infected with HIV/AIDS, as it came to be known.”

PERSAD was among the many groups in the Pittsburgh region that stepped up to care for individuals and families affected by HIV/AIDS during the early days of the epidemic. At a point of confusion and fear, a coalition of local agencies, research institutions, healthcare providers, neighborhood leaders, and faith-based organizations aligned to offer services, comfort, and a sense of community.



Jim Huggins, PhD



'It was about helping people die peacefully'

PERSAD held its first “healing weekend” for seriously ill clients in 1982 (which continues today). Huggins and Forrester found a retreat center and scraped together funding for a weekend of alternative healing methods, spiritual discovery, and grief counseling.

“It was a wonderful experience to bring people together and establish a sense of community, to let them know they weren’t alone. People often felt isolated,” Huggins says. “But in the beginning, we would see people who weren’t going to make it to the next healing weekend because they were going to die. At the very first one we had, we had medical personnel on hand because people were actually dying right there.”

PERSAD established the first AIDS support program in Pittsburgh in 1982, going beyond its original LGBT counseling mission to provide counseling, prevention, outreach, education, training, and advocacy services to people living with HIV and their families. The center hired a

grief counselor to train staff, many of whom were confronting issues of death and dying both personally and professionally.

“We certainly didn’t open PERSAD to be a place where people came for dying services, but that’s what we became for a segment of our clients,” Huggins says. “It was a frightening time. Those of us who were gay and part of the staff were worried for our own health because we didn’t know if we were or would become infected. At the time, they didn’t know if it was airborne, blood borne — there simply wasn’t an answer on how you got it. It was about helping people die peacefully, and helping people who cared and loved them to cope with their grief.”

PERSAD also reached out to the health and social services community, establishing a training and education program to change professional opinions on AIDS. The organization collaborated with healthcare providers, social workers, and mental health professionals to confront the stigmas and fear that led some to deny services to HIV-positive individuals, and train them on universal prevention methods once it was known how the virus spread.

In 1987, PERSAD co-founded Pittsburgh’s first area council on AIDS and also offered LGBT competence training for human service workers. Three years later, the organization played a prominent role in establishing a local chapter of PFLAG, a grassroots organization, which furthers LGBT acceptance and equality through support, education, and advocacy.

“It was difficult for anyone doing work with this population because there were people dying so young — in their teens, twenties, and thirties,” Huggins says. “It could be your brother, your sister, your child. We wanted to engage professional, faith, and community groups to educate, and to make sure those affected had the best quality of life possible.”

'There's no one gay community'

Anthony Silvestre, PhD, was an executive director at a mental health center for LGBT individuals in Philadelphia when he got a call from PERSAD's Randy Forrester. Silvestre and Forrester both served on the Pennsylvania Council for Sexual Minorities, set up by then-Governor Milton J. Shapp to address discrimination based on sexual and gender identity. Forrester told Silvestre about a new NIH-funded initiative at the University of Pittsburgh to document the epidemiology, virology, immunology, and pathology of the HIV virus over time (later called the Pitt Men's Study).

Principal investigator Charles Rinaldo, PhD, professor and chairman of the University of Pittsburgh's Department of Infectious Diseases and Microbiology, had previously enrolled small cohorts for pilot projects examining the potential cause of AIDS. But researchers for the Pitt Men's Study were vexed by one question: How could they convince thousands of gay and bisexual men to enroll and trust them with sensitive health information in a climate that was less than welcoming for sexual minorities? Forrester thought Silvestre, a community organizer with a background in sociology, was the ideal recruiter. Silvestre moved across the state to take up the challenge.

"It was clear that we had to overcome some serious obstacles," says Silvestre, co-investigator of the still-ongoing Pitt Men's Study and a professor in the Department of Infectious Disease and Microbiology. "There was a sodomy law on the books until 1980. There were still police raids in gay bars, and gay people could be subject to violence and job discrimination. In order to get people to trust us with very sensitive information, we enlisted local leaders."

Silvestre accomplished that by establishing a Community Advisory Board comprised of racially diverse male and female representatives of Pittsburgh's various gay and bisexual communities. The board members served as liaisons between study personnel and the staff and helped recruit participants.

"We invited people into the research as active advisors and expert consultants," Silvestre says. "We mapped the community so we could find formal and informal leaders from the wide number of communities out there — there is no one 'gay community.'"

The Community Advisory Board was part of a larger social marketing campaign for the Pitt Men's Study, which established credibility by getting endorsements from peers and connecting participants with health education and employment opportunities.

"Most people joined the study through friendships and word-of-mouth, rather than any kind of formal advertising," Silvestre says. "We went to various organizations — a gay and lesbian community center, coffee houses, the Metropolitan Community Church, motorcycle clubs. Bar owners had their own group at the time, and they offered support by organizing



Anthony Silvestre, PhD

We Join All

PITTSBURGH

In Welcoming

THREE RIVER'S IV

We Wish The

Pittsburgh Motorcycle

Club

and its

Brother Cl

a

Successfu

and

Save Ru

The



15 85
"I WON'T GET AIDS
BECAUSE..."

I
WASH
AFTER
SEX

I'M
NOT
PROMISCUOUS

THERE'S NO
AIDS IN
PITTSBURGH

I ONLY
DATE
CLEAN
MEN

I ONLY
GO OUT
WITH MEN
I KNOW

IF I DIDN'T
GET IT YET
I WON'T

THESE WON'T PREVENT AIDS
FIND OUT WHAT WILL

Call (412) 624-2008

TO JOIN PITT'S AIDS PREVENTION PROJECT

Straight Talk About AIDS

We'll be at the Tavern Guild's Labor Day Picnic at North Park on September 3 to answer questions and to enlist support for the Pitt Men's Study.

Do it for your health. For more information, Call (412) 624-2008



University of Pittsburgh

OUT / AUGUST 1984 / PAGE C5

The Pitt Men's Study ran advertisements in *Out* newspaper and other local publications in an effort to encourage gay and bisexual men to enroll in the program and trust them with sensitive health information.

volunteers and giving space for educational activities. Staff attended to learn about HIV/AIDS so they could become peer educators. They even handed out cocktail napkins with AIDS quizzes on them. The gay community didn't have many formal institutions at the time, so we connected with these social hubs to show people the benefits of participating in the study."

The Pitt Men's Study eventually enrolled a cohort of more than 3,000, yielding important insights on HIV transmission and serving as a springboard for further research on disease prevention and the development of an effective treatment that combined a variety of monotherapy antiretroviral drugs, commonly referred to as the "AIDS cocktail." None of that would have been possible without expanding the study's mission by seeking the counsel of Pittsburgh's LGBT community and showing sensitivity to their broader social needs, Silvestre notes.

"At that time there were few community groups willing or able to work with this population, so we received many requests for help," Silvestre says. "That included people dealing with employment discrimination, people caring for those whose HIV progressed into AIDS, and people who were worried about being infected. By providing services, we let people know that we weren't simply a data collection project. Our concern extended beyond just getting information — we were concerned about the health and well-being of the community."

'People were getting off their death beds to talk'

Shortly after the Community Advisory Board was formed, it became clear to the LGBT activists involved that Pittsburgh's HIV-positive population needed additional support. Board members and Pitt Men's Study staff received a flood of anxious calls: What do I do if I think I'm infected? How do I care for my sick son or daughter? Whom can I talk to if I'm being harassed at work? The demand for information and services stretched beyond the capacity of what was available at the time.

Community activists took matters into their own hands in 1985. Led by Kerry Stoner until his untimely death in 1993 from AIDS, the group established the Pittsburgh AIDS Task Force (PATF). An all-volunteer staff during its first four years of operation, PATF offered legal services to those facing discrimination, and emotional support to those dying from AIDS through a "Buddy program."

Pamela Vingle was among PATF's original group of six paid staff. She arrived to support an effort that had been until then entirely volunteer driven. Vingle had worked with the Program for Female Offenders since 1978, bonding with IV drug users trying to get clean — including some who later discovered that they had AIDS. "I realized in those encounters the deep humanity in those women, whose lives had been so much less fortunate than mine," Vingle says. She also witnessed the heartache of families coping with AIDS through a co-worker,



who worried about her sick brother and wondered whether jail staff would bar her from the facility out of fear that she could transmit the disease.

When Vingle joined the staff at PATF in 1988, a group of 60 volunteers had already set up a Buddy program to connect volunteers to provide needed support and care to those living with AIDS. The new staff supervised the growing number of volunteers serving on the hotline, handled casework, operated an education and outreach department, and set up weekend-long trainings for new volunteers, among many tasks.

The volunteer community could at the time rely on a small group of dedicated physicians. Recalls Vingle, “While individual doctors were seeing individual patients, there were a handful who openly welcomed and accepted patients with AIDS. There were no treatment protocols yet, so these doctors and their patients used whatever information they could gather to develop treatment plans. They learned together. I think especially of Marty Seltman, Jerry Rabinowitz, Bob Arnold, Paul Rogers, Sharon Riddler, and Susan Hunt. I also think of Larry Leahy — he was the only dentist on our list back then.”

The work took an emotional toll, so the Buddies started their own support group to deal with the constant loss of people living with AIDS who had become close friends. In collaboration with the Pitt Men’s Study, the Pittsburgh Center for AIDS Treatment (a dedicated Ryan White HIV primary care unit at the University of Pittsburgh), PERSAD Center, the Shepard Wellness Community (the only AIDS community center in western Pennsylvania, founded by Father Lynn Edwards) and others, PATF’s volunteer staff swelled to 500 active people, with another 500 available on an as-needed basis. Volunteers came from all walks of life. They included people living with AIDS, doctors, clergy, attorneys, government officials, community workers, family members, and even former offenders whom Vingle knew.

The community also borrowed some of ACT UP’s tactics as well. To lobby the State government in Harrisburg for increased funding for the Pittsburgh area from the Ryan White funds (most state funding went to Philadelphia), Vingle and others organized HELP (the HIV Emergency Lobby Project). They conducted a letter-writing campaign, lobbied local legislators, and helped organize demonstrations. One downtown Pittsburgh demonstration

Pittsburgh AIDS activists in the 1990s, including Pamela Vingle, seated at center.

look like a funeral. Participants circulated handouts of the governor with a bloody handprint across his face. Funding for western Pennsylvania increased. Says Vingle, “We all had to be activists in that way, because nobody else was looking after us.”

They also helped people living with AIDS to offer their perspectives to the community. “People were literally getting off their death beds to talk,” Vingle says.

Dana Phillips (who would establish the Ryan White fiscal agency at the Jewish Healthcare Foundation in 1992) shares Vingle’s awe at the courage shown by so many: “In the early days of the epidemic in Pittsburgh there were individuals who came forward at sometimes great risk to themselves, talked about the epidemic, talked about what was going on with them, and really put themselves out there.”

Says Vingle, “We could not have made things happen had they not done that. That was crucial because it became a situation in which everybody knew somebody. I think of a fellow name Joe Doaks. He and his mother were active PATF volunteers and spoke frequently about the epidemic and its impact on their lives. They made such a strong personal statement just by who they were and how they comported themselves. The best was when Joe was recognized by the local county commissioners for his outstanding service.”

Adds Phillips, “In fact, an important piece of the Allegheny County Health Department work at that time was helping to find people who were willing to talk and willing to share their stories. It humanized the epidemic and helped bring various communities together to help.”

“When you were diagnosed back then, many were fortunate to live just six months,” Vingle recalls. “But every day you saw people rise to the occasion. The whole community was a family. It was different from any nonprofit I’d ever worked for. You were truly your brother’s keeper.”



PHILANTHROPY RESPONDS: FUNDERS CONCERNED ABOUT AIDS

Michael Seltzer can’t forget the panicked call he received from his good friend, Bob White, during the summer of 1985. Bob’s body was shutting down from HIV, then commonly referred to as “gay-related immune deficiency disorder.” He knew that Michael was an ardent LGBT activist in New York and had friends at the newly-established Foundation for AIDS Research (amfAR). Bob pleaded: Did Michael know of something — anything — promising to stave off near-certain death?

Seltzer contacted Dr. Mathilde Krim, amfAR founder, and she directed Bob to a trial at the Pasteur Institute in Paris for an experimental drug called HPA-23. A few hopeful Americans — movie star Rock Hudson among them — flew overseas to participate in the trial led by Dr. Luc Montagnier, a virologist who in 1984 discovered that the HIV retrovirus causes AIDS. Researchers tried to dissuade Bob from making the trip, noting they couldn’t guarantee any results in exchange for his leaving loved ones behind in San Francisco.

“Bob was so assertive — and so desperate to live — that he took the next flight to Paris,” Seltzer says. “I joined him for two weeks to offer support. But the drug was ultimately proven ineffective, and Bob died in San Francisco in January of 1986.”

Seltzer, then a consultant for the Ford Foundation and New World Foundation, and fellow grant makers felt a disconnect between the severity of the AIDS epidemic and the government’s tepid response. It was an era in which U.S. President Ronald Reagan didn’t say the word “AIDS” in public until 1986, and Indiana teenager Ryan White was kept from attending classes because he had the disease. The same year that Bob died, the National Academy of Sciences (NAS) called for a \$2 billion investment to address a “national health crisis” that was the leading cause of death in New York and San Francisco among men age 25–44 and women age 25–34; yet, the federal government spent barely a quarter of NAS’s suggested total — \$508 million — on HIV/AIDS programs in 1986, according to the Congressional Research Service (CRS).

“The response to AIDS was the first public health crisis in the U.S. financed through raffle ticket sales because of the stigma that was attached to it,” Seltzer says. “We had an expression in those days. There were those infected who were carrying HIV, and there were those affected who watched loved ones, colleagues, and friends suffer. We were prompted to take action, to fill the void, and galvanize the philanthropic response to the AIDS pandemic.”

A small group of grant makers in New York and San Francisco took action by establishing Funders Concerned About AIDS (FCAA), a national network of philanthropic organizations devoted to increasing the resources available for AIDS treatment and prevention, advocacy, education, and research. Seltzer served as FCAA’s executive director (from 1987 to 1995) while Joyce Bove, vice president for grants at the New York Community Trust, chaired the board. Members also included Dana Phillips and Karen Wolk Feinstein (President and CEO of the Jewish Healthcare Foundation). Seltzer and Bove reached out to Grantmakers in Health (GIH) President and CEO Catherine McDermott, who agreed to become a co-sponsor of FCAA’s programs. While FCAA would eventually mobilize a cadre of grant making leaders and the broader public, the organization first had to raise awareness that AIDS funding was far more than a philanthropic niche.

“The response to AIDS was the first public health crisis in the U.S. financed through raffle ticket sales because of the stigma that was attached to it.”

—MICHAEL SELTZER, FOUNDING EXECUTIVE DIRECTOR OF FUNDERS CONCERNED ABOUT AIDS (FCAA)

“Our first briefing for grant makers took place at the Blue Cross Blue Shield office. We had a total of four people in the audience and four people on the panel,” Seltzer says. “Those were the odds we were up against. Some of the barriers we faced were institutional in the sense that foundations tend not to fund what they consider single-disease issues because there are typically large, publicly and charitably funded organizations working in that area. So we quickly found that we had to explain that this was more than a single disease — it was a threat to the public health.”

AIDS. Something good must come of it.

The core message that FCAA developed — and still uses today — is that every philanthropic organization’s program areas have a connection to AIDS-related issues. FCAA launched an advocacy campaign to show how a broad spectrum of funders and community members could fight AIDS and address the social inequities of the disease. Their tag line was: *AIDS. Something good must come of it.*



Marni Vilet

“If you’re involved with civil liberties, this is clearly a case where people with AIDS are being discriminated against on the basis of their disease,” Seltzer says. “If you’re involved with economic development or housing, there are people with AIDS losing their jobs and needing a place to live.”

The FCAA’s New York meetings were open to the public and attracted local community organizations, place-based foundations, and conversion foundations, says Marni Vilet, an FCAA member who previously served as a GIH board member and was president of the Kansas Health Foundation. FCAA members also conducted workshops at GIH and Council on Foundations conferences, providing a national platform to show how supporting AIDS funding furthered the goals of any philanthropic group.

“FCAA wanted to get the topic of AIDS in lots of other conversations with funders working on everything from health care to health policy to public health,” Vilet says. “We also stretched our audience by inviting funders working on environmental issues and social policy. People were challenged to find out how their resources could be used to make the biggest difference, be it research, home health care, or getting people insured. We developed partnerships and programs that demonstrated value to the public sector.”

Those close ties spurred the development of the National-Community AIDS Partnership (now called AIDS United) in 1988. Led by the Ford Foundation, the Partnership included philanthropic and corporate donors who created a national funding source to expand the capacity of local organizations to care for people living with AIDS and their families as well as launch HIV prevention programs. Those groups joined the Robert Wood Johnson Foundation (RWJF), which established a dedicated AIDS Health Service Program (a template for the federal Ryan White CARE Act) in 1986. Other early HIV funders included the New York Community Trust, as well as the San Francisco, Aaron Diamond, MacArthur, and Rockefeller Foundations. The federal government followed suit with additional support for treatment and prevention, increasing HIV/AIDS funding to \$3.83 billion by 1991, according to the CRS.

“There was a dual effort going on in the early days,” Seltzer says. “One was getting grant makers to the table. The other was creating a whole generation of new service, prevention, care, and advocacy organizations. We were illuminating other issues related to health and disease that we as a civil society needed to recognize and for which we needed to find and fund solutions. It was one of the finer moments in philanthropy’s history. Grant makers stepped forward when other organizations were avoiding the issue.”

JEWISH HEALTHCARE FOUNDATION: FISCAL AGENCY 1992-2000

Dana Phillips came to Pittsburgh from Chicago, eventually working first for The Pittsburgh Foundation and then for the Jewish Healthcare Foundation, where she was instrumental in the Foundation's application to be the southwestern Pennsylvania fiscal agent for the Ryan White Part B funds (which provides grants to States and Territories to improve the quality, availability, and organization of HIV/AIDS health care and support services).

"In the late 1980s when I moved to Pittsburgh from Chicago, I had already been involved as a volunteer in the AIDS epidemic," Phillips says. "I raised the issue, but many felt it wasn't really a big issue in Pittsburgh at the time. About four months later, when I went to work at The Pittsburgh Foundation, I set up a meeting with Allegheny County Commissioner Tom Foerster to learn more about what was going on in the county and region. One of the things you have an opportunity to do when you work for a foundation is to access people for dialogue on all kinds of things." The meeting led to dialogue with Foerster's executive assistant Bob Nelkin, then with Dr. Bruce Dixon, Director of the Allegheny County Health Department.

The major insight Phillips gleaned from these meetings was the lack of alignment between the community's multiple responses to the epidemic. "It became very clear to me that there wasn't any connectivity between what people in the community were trying to do and what the Pitt Men's Study was trying to do, and what the Health Department was trying to do. They just didn't have what I would call natural bridges."

So Phillips invited representatives from all the major community-based organizations working with the HIV-positive population to a series of meetings at The Pittsburgh Foundation. Out of those meetings grew the Southwestern PA AIDS Planning Coalition (the Coalition). With support from Sholom Comay (chairman of The Pittsburgh Foundation) and John Heinz (chair of the Howard Heinz Endowments), The Pittsburgh Foundation made early grants to the Pittsburgh AIDS Task Force (PATF) and to the Shepherd Wellness Community. Later the Howard Heinz Endowments made a substantial grant to the United Way of Pennsylvania to work with the Pennsylvania Department of Welfare and the Department of Health to lay the groundwork for similar kinds of coalitions to evolve around the state.

The Coalition worked to make services available to people with HIV. For example, describes Phillips, "We had extensive meetings with the community, to which we invited nursing home boards of directors. We wanted them to understand the fact that people with HIV infection were out there. It wasn't a question of whether or not they would serve them; it was a question of whether or not they would *know* that they were serving them, and whether they would be willing to train themselves to provide this service safely. One of the moments that I will never forget is when during such a meeting the chairman of the

"All of it came from ordinary folks like us putting our heads together. Pittsburgh has a long historic tradition of bringing people together around the table to solve its problems."

— DANA PHILLIPS

FISCAL AGENT FOR SOUTHWESTERN PENNSYLVANIA

The Jewish Healthcare Foundation has served as the regional fiscal agent for the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act in southwestern Pennsylvania since 1992. In this role, it is responsible for disbursing approximately \$3 million in annual grants. It also helps AIDS service organizations (ASOs) that apply for funding meet federal and state requirements for program and fiscal management, and conducts monitoring and reporting to improve program efficiency and responsiveness. The fiscal agent also helps streamline and standardize the work being done by the grantees. Most importantly, the fiscal agent is responsible for strengthening the continuum of care and ensures all eligible clients receive the needed services and medical support to live a healthy life.

JHF has reached beyond its traditional fiscal agent role to areas related to quality improvement (QI), community support, stewardship, and leadership. JHF pays grantees within 15 days of receiving their invoices – before the Foundation is reimbursed by Pennsylvania. In addition, on an annual basis, JHF provides grantees with in-kind services beyond what the Commonwealth reimburses fiscal agencies for staff, financial management, and programming. Over the past two years, JHF's in-kind support has approached \$300,000. JHF has always articulated its mission as ensuring the prevention of HIV, as well as the integrity and quality of the safety net for people living with HIV in western Pennsylvania.

board of a nursing facility raised his hand and said, 'Well, I appreciate all of this, but our staff is not prepared. We don't know how to take care of these people.' At which point, a lady from the [Pennsylvania] Department of Health raised her hand, stood up and said, 'Did I just understand you to say that the license you have on the wall of your facility is not a license that you should have because you can't practice infection control?' You could have heard a pin drop."

When Phillips moved to the Jewish Healthcare Foundation in 1992, Pennsylvania had just begun to look for ways to channel the new Ryan White CARE Act funding. "The state felt it was important, to the extent possible, to identify a neutral agency, and Karen Wolk Feinstein [JHF president and CEO] was willing to allow the Jewish Healthcare Foundation to play that very important role," Phillips recalls.

"I think the role was important. The Foundation was new at that point, and relatively small, and had a very clear understanding of what it meant to be a catalyst for action. That has always been one of Karen's strengths and a role that the Foundation has played consistently over time. Once the Foundation became the fiscal agent, we worked to be highly equitable and careful in the granting-making." The Ryan White funding also helped JHF, originally established as a private foundation, to later become a public charity, both supporting the work of charitable organizations and performing charitable work themselves.

With support from the Foundation, in 1992, a community advisory committee had just crafted the *AIDS Action Plan — a Community Commitment*.⁵ The plan detailed the extent of the epidemic in southwestern Pennsylvania: At the time, more than 1,000 people were known to have AIDS in the 11-county region, including half of all those with hemophilia (90 people). Unknown were the number of people with AIDS who returned to their Pittsburgh family and friends for care, but who had been diagnosed elsewhere. Local agencies estimated that perhaps half of their clients came from other regions. Moreover another 2,000–3,000 people were estimated to be infected with HIV, but unaware of their status.

In light of these statistics, and persistent calls for help from local organizations, as well as from people with AIDS and their families and friends, the *Action Plan* made a series of hard-hitting, very specific recommendations for better prevention and testing and for strengthening what had been an ad hoc safety net. These recommendations informed the first round of funding under the new JHF Ryan White fiscal agency. Early grants supported organizations like Verona House which provided a personal care home and hospice support for younger people with AIDS.

In her roughly three years of managing the Foundation's fiscal agency, Phillips worked with the Coalition to plan and set funding priorities, issued RFPs, evaluated proposals, and ultimately, with the approval of the JHF Board of Trustees, distributed Ryan White funds, channeled through the state, to community-based AIDS service organizations (ASOs). "I think that the Foundation played a stronger and more vocal role as each year went by," concludes Phillips.

During this period, community organizations evolved. Almost every county in the region ultimately developed smaller versions of the Pittsburgh AIDS Task Force. Each was responsible for case management, volunteer support, connecting people to one another, and providing health education.

Reflecting on the differences between her experiences in Chicago and in Pittsburgh, Phillips recalls that, "In Pittsburgh, the timing was different. When I was a volunteer in Chicago, it was at a point in the epidemic when people got diagnosed, were cared for only for a very brief period of time, then they died. Fortunately in Pittsburgh, we had the blessing of seeing medications emerge that extended life, so we were more concerned with making sure that people had access to a pharmacy benefit program, helping people stay in care (through case management services), and training providers about the new face of the epidemic as it moved, more and more, into the African American community and particularly impacted African American women."

"I think one of the most amazing things to me is that we were able to consistently say to a squeamish population that AIDS is a health problem. Please forget lifestyle. It has to do with the health of the public. We — the Foundation, the health department, the AIDS service organizations — we were all part of putting forth the message that, 'Of course we're going to deal with this, because this is an issue in our community.'"

THE SHIFT



2000-PRESENT

THE CHANGING FACE OF HIV

By early 1993, AIDS became the leading cause of death among all Americans ages 25 to 44.⁶ At the same time, the FDA approved *Saquinavir* — one among what would be a growing new class of HIV drugs called protease inhibitors. “Before long, people with advanced AIDS were climbing out of their sickbeds and resuming normal lives, a phenomenon that came to be known as Lazarus Syndrome.”⁷

Notes Kanel, “A single breakthrough — highly active antiretroviral drugs in novel combinations — completely changed HIV disease, from a condition of serial acuteness, to a manageable chronic medical problem.” Beginning in the early 1990s, death rates began to rise more slowly than the infection rate.

As the 1990s came to a close, both the nature of the disease and the populations most affected began to change. New York City’s health department conducted a survey in 1999 finding that 18 percent of black gay respondents were infected with HIV — a rate that doubled two years later (compared to 3 percent of white gay respondents).⁸ By 2004, the National Minority AIDS Council reported that African Americans “account for 51 percent of all new HIV infections in 32 states, but make up only 13 percent of the population in those states.”⁹ And testing for the virus became easier: in March 2004, the FDA approved the first rapid saliva HIV test.

Cates left the CDC to head the HIV Prevention Trials Network (HPTN) from 1999 to 2007. HPTN was a consortium of universities, research NGOs, and domestic and international sites conducting research which was, in the words of Cates, “a game changer.” For example, an HPTN study published in 1999 (HPTN 012) found that *nevirapine* therapy could reduce by 50 percent the rate of maternal-to-child HIV transmission in low-resource settings and could be made available through global aid, curbing transmission in Africa.

As the nature of the epidemic began to change, the CDC began to adopt an HIV prevention counseling model that was client-centered, rather than disease-centered. Says Cates,

KEY DATES: TREATMENT & TESTING FOR HIV

1983
Scientists at the Pasteur Institute in France identify the virus.

1985
First commercial blood test (enzyme-linked immunosorbent assay or ELISA) to detect antibodies to HIV approved. Screening of the U.S. blood supply begins.

1987
The FDA approves the nucleoside reverse transcriptase inhibitor (NRTI) zidovudine (or AZT) — the first antiretroviral drug for AIDS. Toxic to some, AZT nevertheless extends life expectancy for some infected patients.

1994
First oral HIV blood test approved.

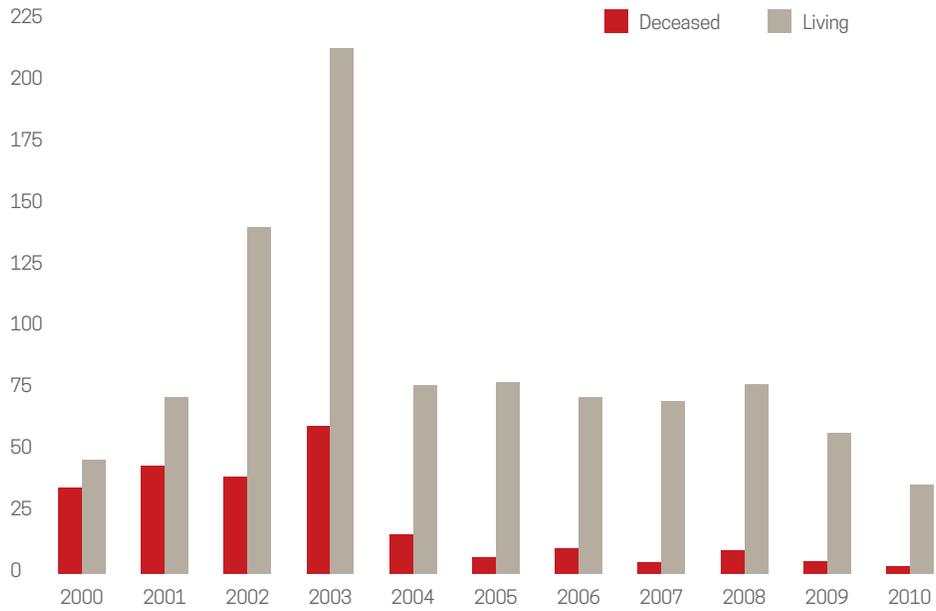
1995
The FDA approves the first in a new class of drugs called protease inhibitors (PIs). In combination with other HIV medications, the treatment known as the “AIDS Cocktail” — or highly active antiretroviral therapy (HAART) — becomes the new standard therapy by 1997, leading to dramatic improvements in life expectancy.

1996
First HIV urine test is approved.

2004
The FDA approves the first saliva rapid, 20-minute HIV test.

AIDS IN ALLEGHENY COUNTY

AIDS cases living and deceased by year, Allegheny County, 2000–2010



Source: Allegheny Health Department 2010 Annual STD Study

“Data have shown that client-centered counseling has been the way to go, not just for HIV, but for sexually transmitted infections in general — and other conditions as well. You meet the client where their world is and work with them to develop behaviors that serve their needs. That’s the only way you’re going to get adherence to safer behavior, whether it be HIV or cardiovascular disease.”

Continues Cates, “Just like syphilis — we had to find syphilis cases and treat them. Now with HIV, we have to find HIV cases and treat them. So the two worlds of HIV and STD became much closer. Meanwhile, for syphilis, CDC was finding that you can’t *just* find individual syphilis cases; you have to also interact with the community and have population approaches so the community supports all of these measures.”

By the mid-2000s, even though in many agencies HIV remained a separate bureaucracy from those focused on other sexually transmitted infections, both were, in Cates’ words, “using in essence the same combination of individual level and community level prevention.”

This approach received exciting support from the scientific community with another HPTN study published in 2011 (HPTN 052). Says Cates, “The study demonstrated that the most effective way of preventing spread was to find and treat the infected person/partner — that by treating them you could reduce the virus in their blood if they were to adhere to treatment lowering viral loads to levels that rendered them virtually non-infective. It was an amazing study. It was deemed *Science* magazine’s discovery of year and it has resulted in increasing amounts of U.S. and other funds . . . going into treatment not only to help the prognosis of the infected person, but also to reduce their ability to spread the virus to others. And that’s a much, much, much more effective way of practicing public health. We were able to eliminate small pox because we were able to identify the index case and vaccinate around them. That led to the most important public health discovery of my time — the elimination of small pox. The same principle is now being applied to HIV. We want everyone to find out their infection status; and it’s good news no matter what happens, because if you’re not infected, then you can take steps to remain un-infected. But if you are infected, better that you know now than waiting until later down the road when it will be much harder to treat you. So it ought to be a badge of honor for people to know their infection status.”

JEWISH HEALTHCARE FOUNDATION: FISCAL AGENCY 2001-2014

As Barb Feige took over management of the fiscal agency at JHF from Dana Phillips in 1995, things were already changing. Recalls Feige, when JHF began its fiscal agency, it “was the cusp of the period when the worst of people dying was coming to an end with the start of antiretrovirals. The population was still primarily white gay men, but it was quickly spreading to African Americans, IV drug users, and the female partners of male IV drug users. AIDS was still the number one public health issue. It was in the headlines and great

things were happening at the same time. As early as 1995, we'd already begun changing from helping people to die (from funding hospice care, making sure they have wills and food, and making sure funeral homes will take them) to starting to make sure that people have the medications and the health insurance they need. That just accelerated — so that our priorities changed from funding case management to paying for new medications.”

The mix of agencies also began to change. “Established organizations like the Pittsburgh AIDS Task Force and PERSAD were both still going strong. But there were beginning to be more community-based organizations in the African American community, especially as more churches started to come to terms with how they were going to deal with HIV,” says Feige.

Typical of the changing focus, Prevention Point Pittsburgh was founded in 1995, when Caroline Acker and James Crow set up a cart on a Hill District street corner near bus routes and heavily-trafficked avenues. The service they offered — a needle exchange program to prevent the spread of blood-borne, injection-related diseases — was (at the time) not legal. But Acker, who had recently moved to the region from California to take a job at Carnegie Mellon University, considered needle exchange an act of civil disobedience and a public health imperative. Rates of HIV and Hepatitis C were climbing among Allegheny County’s 10,000-plus injection drug users.¹⁰



Caroline Acker

“I got involved because my brother died of AIDS,” says Acker, a medicine and public health historian at CMU. “He was an artist in New York. There has also been addiction in my family. The first time I heard about needle exchange, this light bulb went off — this intersection of disease and addiction. I connected with James Crow, an LGBT activist who was trying to establish a needle exchange program in Pittsburgh. We both saw the urgency of needle exchange. It had to be done.”

During the organization’s first seven years, Acker, Crow, and a small band of volunteers operated an “underground” needle exchange program, handing out sterile syringes in the Hill District at the risk of arrest and without the support of federal or local government. Congress banned federal funding for needle exchange programs in 1988, concerned that they could promote drug use. The ban remains on the books despite numerous studies suggesting that the programs reduce the spread of HIV and other diseases without increasing illicit drug use.¹¹

Just one person visited Acker and Crow’s cart on their first day in 1995. Over time though, Prevention Point Pittsburgh addressed potential clients’ skepticism through word of mouth, establishing credibility with experienced users and sellers who had large social networks.

“The very first person — the one person on that first day — we got to know him very well,” Acker recalls. “He was maintaining a shooting gallery near where we were set up. One of the things that he told us is that people were afraid to come to a card table on the street



Caroline Acker, left, Stuart Fisk, and Laura Horowitz, all volunteers with Prevention Point Pittsburgh, assemble supplies for part of their underground needle exchange in 2000.

corner. Some people actually thought this was a set-up by police to entice people to get needles and then arrest them. He ran a pretty busy operation selling drugs. People moved in and out of his place, and they all got the word.”

Another early partner was a transgender Hill District resident, who served as a conduit between users and Prevention Point Pittsburgh volunteers. “She would bring us questions and concerns that they had, and we would provide information that she took back,” Acker says. “Building trust through those relationships helped make referrals possible. People came to us to get services when they would not go elsewhere for fear of being turned down or treated badly.”

Prevention Point Pittsburgh was established at a time when new antiretroviral drugs shifted AIDS from a death sentence to a chronic, manageable illness. Injection drug users accounted for about eight percent of new HIV cases, according to the Centers for Disease Control and Prevention.¹² Acker viewed needle exchange programs as a life-saving, evidence-based way to improve public health.

“Infectious diseases often spread from one demographic group to another,” Acker explains. “To whatever extent a person might feel insulated from HIV because they’re not gay or a drug user, they may have sex with a person who has been exposed, or may be born to a mother who is HIV-positive. There are ways that infectious disease can leak out of the groups where they’re concentrated. That’s the rationale for everyone having a stake in controlling an infectious disease like HIV/AIDS.”

In 2002, Allegheny County declared HIV/AIDS a health emergency, allowing the Allegheny County Health Department to sanction a two-year Prevention Point Pittsburgh needle exchange pilot program. JHF, which had been administering grants for HIV/AIDS services and prevention efforts in southwestern Pennsylvania for the past decade, immediately awarded a two-year, \$30,000 grant for HIV/AIDS prevention efforts to Prevention Point. Acker says that JHF’s support helped the organization demonstrate the needle exchange



PITTSBURGH RED



Jeanne Grazier, Carolyn Ward, and Rigardo Rush listen to Pittsburgh Mayor Luke Ravenstahl's press conference to discuss World AIDS Day on December 1, 2009.

program's effectiveness and gain the county's blessing to continue lowering the Pittsburgh region's burden of disease.

"JHF was critical in the early days, helping us expand and develop a more secure foundation for our work," Acker says. "They allowed us to go from a guerilla group to an organization with a better capacity to add additional services, apply for other monies, and hire staff. There are people in every neighborhood in Pittsburgh who need these services."

Other initiatives reflected the urgency not only of preventing transmission but getting people tested so that they could access new, life-saving medications.

Barb Feige recalls that the African American community began to have "programs that worked through beauty and barber shops — doing health education, making condoms and educational material available. We also began to see programs that tried to reach people in their communities. For example, free testing became available at community sites, allowing for a 'normalization' of testing that would override the feared stigma of walking into an ASO's office."



Barb Feige

Enter Quality Improvement

Just as the evolving nature of the HIV epidemic called for a new focus on medications and remaining in care, the focus of the Foundation's fiscal agency similarly became more proactive. Having already established the efficacy of its healthcare quality improvement training programs, the Foundation began to search for ways to integrate support for improving the quality of the care continuum for people living with HIV among the agencies granted Ryan White funds.

Recalls Jason Kunzman (JHF CFO and fiscal agency manager from 2003 to 2010), "By the mid-2000s, the question became: How does the system of care need to change to meet the needs of a chronic condition? People living with HIV weren't just getting services for a finite period of time, but for a prolonged period. So service delivery needed to move from responding to an emergency situation to developing a true continuum of care. And that was the Foundation's sweet spot. Timing, leadership, willingness to fund and seed initiatives — all are roles that the Foundation effectively plays."

The Foundation's own emphasis on quality improvement was significantly strengthened by the Ryan White program's federal oversight agency, the Health Resources and Services Administration (HRSA) of the Department of Health and Human Services. In the mid-2000s HRSA introduced quality management requirements for Ryan White grantees.

Remembering the change, Kunzman remarked, "The challenge was that, as fiscal agent, we were responsible for the whole procurement process. This meant that we had to run the RFP process, take in proposals, and set up a review committee with leaders in the field of HIV/AIDS care delivery from across the state. But as we also began to weave quality

of care requirements into RFPs and began looking for related skills among those serving on the review committee, there was resistance. This period marked the transition from a ‘services, services, services’ model, to figuring out how the patients of various providers were actually faring in terms of outcomes — and then using that data to make procurement decisions. It was difficult because the Foundation held the system accountable for making sure that there were higher quality services truly meeting needs, as defined by outcomes and not just processes.”

The Foundation’s commitment to quality improvement among the local cohort of community-based AIDS service organizations extended well beyond ensuring that each ASO had a documented quality management plan. Working together with the Pennsylvania Department of Health’s Division of HIV/AIDS, JHF developed the PA HIV Web Portal — an online quality management tool to provide three services to ASOs in Pennsylvania: (1) a clear, accurate, and easy-to-use data reporting clearinghouse; (2) Quality Improvement (QI)/Quality Management (QM) education resources; and, (3) organized and clear access to other resources and content. The portal unified Ryan White providers across the Commonwealth.

It was the first time that Ryan White Part B providers uploaded their performance measurement data in a single location. They can create scorecards; and compare themselves to [de-identified] other providers and state averages; and print out bar graphs, metrics, and trend reports.

Says Kunzman, “We were able to help providers visualize the impact of the work they were doing.”

Reducing Readmissions as a Quality Improvement Goal

Richard Smith, current program director for the Jewish Healthcare Foundation’s fiscal agency, joined the Foundation in 2010, having been intensely involved with ASOs, first in Pittsburgh (PATF and PERSAD Center) and then in north Philadelphia (at the Immunodeficiency Clinic at Einstein Healthcare Network). He held various positions, including prevention worker, crisis counselor, tester (via PATF; Pittsburgh was one of ten U.S. cities that tested Oraquick — a 20-minute oral HIV test), and group therapist for long-term HIV survivors and those with new HIV diagnoses. He brought to the Foundation an awareness of the various challenges faced by ASOs, and hard-won understanding of the different populations affected by the virus. Particularly relevant to the Foundation’s healthcare quality mission, Smith also had been the quality improvement coordinator at Einstein.

Smith recalls that, “This was shortly after HRSA first introduced quality improvement (QI) into its requirement for Ryan White funding recipients. Although the QI requirements were evolving, it was clear that we needed to begin measuring things that we weren’t looking at before to see whether the programs and services provided were actually making a difference in clients’ lives.”

A combination of disturbing trends led Smith to leave direct client work — and reminded him that the epidemic was still not over. “When I was at Einstein we began to see more teenagers who were pregnant and HIV-positive,” recalls Smith. “My job was to relay their test results. That was always hard. There was always crying. Then people began coming in who were very, very sick, with extremely rare forms of cancer — unusual since effective medications had become available. I wasn’t emotionally prepared for this kind of devastation.”

So in 2010, he was ready to make a difference in other ways when the Jewish Healthcare Foundation asked him to move to Pittsburgh to work with Scott Rosenblum, who was then managing the JHF fiscal agency (Smith took over management of the fiscal agency from Rosenblum in 2012). At the time, the staff was just beginning to grapple with the implications of a recently-released study on patterns of admission and readmission among HIV-positive patients in southwestern PA. The study had been initiated following the Foundation’s request that the Pittsburgh Regional Health Initiative (PRHI) research team (PRHI is a supporting organization of JHF) study the characteristics of hospital admissions among HIV patients in southwestern PA.

The researchers analyzed data made available by the Pennsylvania Health Care Cost Containment Council (PHC4) that characterized the hospitalizations of all 562 HIV-positive adult patients who had been admitted to southwestern PA hospitals between 2007 and 2008.¹³ The researchers dissected some of the reasons underlying a 30-day readmission rate of 27 percent for HIV-positive individuals (50 percent higher than average 30-day readmission rates). Not only are hospitalizations disruptive to the life of the patient (and carry with them their own risks), they also represent some of the most intensive expenditures in the health system. Importantly, many hospitalizations can be prevented. The study finding pointed to promising strategies.

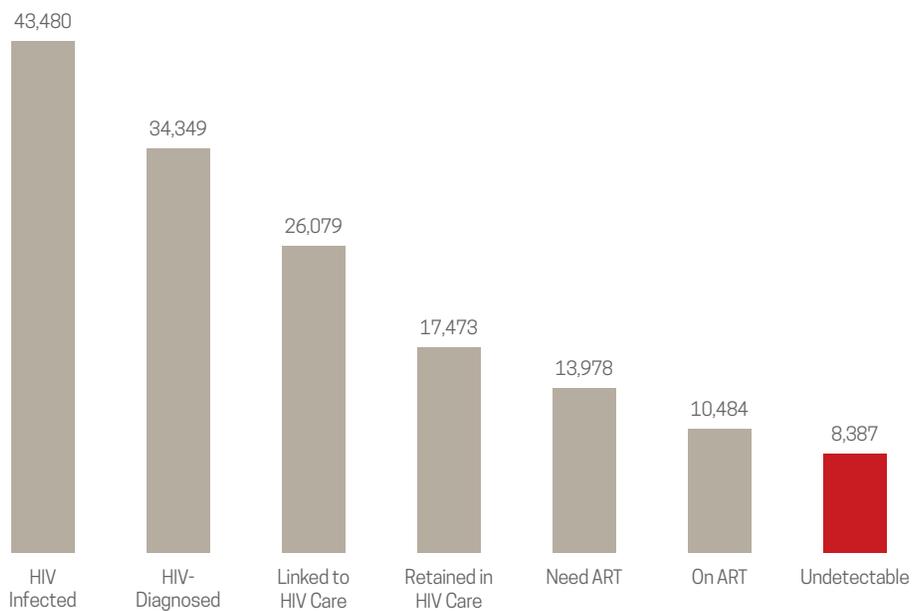
Susan Elster, one of the study’s authors, summarized the findings: “We learned that many of the admissions of HIV-positive patients were for common chronic diseases. This finding was consistent with the fact that HIV had become a chronic illness and that patients were living long enough to, for example, contract diabetes. The findings pointed to the need for multi-disciplinary care teams to prevent readmissions, as is best practice for chronic disease management more generally.”

The researchers also found that two-thirds of 30-day readmissions occurred within just two weeks of hospital discharge, highlighting the need for better care transitions and “hand-offs” of patients between hospital and community-based post-discharge care.

Responding to these findings, Foundation staff, led by previous fiscal agency program manager Jason Kunzman, designed and implemented a hospital readmission reduction project. With grant support from The Pittsburgh Foundation, Smith and his team launched the Readmission Reduction Project with Allegheny General Hospital’s Positive Health Clinic

PENNSYLVANIA CASCADE:

Of those who have been diagnosed HIV-positive, only 24% have suppressed viral loads (i.e., have the HIV virus under control).



Pennsylvania Department of Health. (2013). The Continuum of Engagement in HIV Prevention/Care. Presented at Pennsylvania State HIV Capacity Building Meeting. State College, PA.

(PHC). One of two regional, federally-funded HIV clinics under the Ryan White CARE Act of 1990, PHC provides primary medical care and intervention services for approximately 700 people living with HIV.

Using PRHI's quality improvement methodology (Perfecting Patient CareSM) and on-site coaching, an interdisciplinary care team redesigned the rooming process in the clinic, strengthened and standardized communication between the clinic and the hospital's emergency department, and improved tracking of hospitalized patients. The new processes made operations more effective and efficient. It also resulted in better communications with community-based organizations whose services could support patients following hospital discharge. These efforts seem to have paid off. Although the project ended before long-term data could be collected, one year into the project, PHC recorded a 52 percent reduction in 30-day hospital readmissions for individuals with HIV/AIDS.

Reflecting on this project, Smith notes that, "It was a turning point for the ASO community in Pittsburgh. While the Positive Health Clinic was the focus, we discovered that getting readmissions down meant involving the other community organizations that support people living with HIV. We knew that they would need to work closely together to build a true safety net, but found that many hadn't really worked together at all. So, it was an opportunity to try and help improve communication. As a result the community has become a lot more cohesive in working together."

The Minority AIDS Initiative

Despite the fact that there have been significant advances in medical care and antiretroviral treatment (ART) for people living with HIV, their impact is limited by the fact that at the state and national levels nearly one in six people with HIV don't know they are infected¹⁴ so do not take early actions to suppress the virus and can pass it along to others without knowing it. Even among those who know they carry the HIV virus, fewer than 40 percent take HIV medications as prescribed. And of those who take HIV medications regularly, only 26 percent have suppressed viral loads (i.e., have the HIV virus under control).¹⁵ The numbers of individuals living with HIV/AIDS who are actually receiving the full benefits of the medical care and treatment they need, often depicted in a model known as the HIV/AIDS treatment cascade, is visible also among those living with HIV in Pennsylvania (see figure on previous page).¹⁶

Gaps in diagnosis, linkage to and retention in medical care, and access to treatment contribute to this result. Furthermore, for minority populations, significant health disparities affect outcomes. For example, among all HIV-positive individuals, only 21 percent of African Americans and 26 percent of Hispanics/Latinos achieved viral suppression compared to 30 percent of Whites.¹⁷



MOTIVATIONAL INTERVIEWING

“Where are you at with your medication?” asked Cheryl Kane, a case manager at AIDS Resource Alliance in central PA, of a client she hadn’t seen in weeks. The client had been HIV-positive for years, had sporadically visited the ASO, and had been able to keep her viral load undetectable. Until her last appointment, that is. She was given a prescription for antiretroviral drugs, but she said she’d lost it in a friend’s car. She’d promised to get a replacement prescription filled, but still hadn’t done so.

“She told me that she didn’t really want to take the medications,” Kane recalls. “She said that she never had to before, and she was doing just fine. That’s when I asked her: what are some of the positives that could happen in your life if you started taking your medication?”

The client mentioned that she had an eight-year-old son whom she adored. If she took her medication, she could be there to provide for him. “She had been incarcerated several years before, and she never wanted to leave him again,” Kane says. “That was her incentive to start taking her meds and coming to her appointments regularly.”

Kane re-engaged the client in care using the training she received from PRHI on Motivational Interviewing (MI), a conversation style in which healthcare professionals and patients work together to discover the patient’s own reasons to make positive behavioral changes and strengthen their commitment to change. Healthcare professionals and patients are treated as equal partners, each possessing useful knowledge that can

help align the patient’s actions with their stated life goals and values.

Kane, a ten-year veteran at AIDS Resource Center, says she has to resist the ‘righting reflex’ when talking with patients. Before she provides information, she now asks herself: Is this something that the client asked for?

“I now know that if they don’t want it, then they’re not yet ready to examine that information or broach that subject,” Kane says. “If that happens, I ask about other steps that the client can take to improve their health. I talk to them about what they want, and what they’re ready to talk about.”

The central premise for using MI in this initiative is that linking and retaining people living with HIV in medical care is about relationships. Successfully engaging people in HIV care requires not only the strong organizational processes with which QI can help, but also compassionate and communicative frontline staff.

“We have much more success using a client-centered MI approach instead of just saying, ‘Here is what you need to do,’” Kane says. “That creates resistance. MI has helped me realize that it’s not about me or what I know – it’s about trying to get to know someone well enough to figure out what drives them to take control of their health.”



As the readmissions reduction project came to a close, an opportunity to work with ASOs to focus on essential aspects of prevention presented itself.

As part of the JHF fiscal agency, in April 2012, JHF received an additional \$1.2 million in Minority AIDS Initiative (MAI) funding from the Pennsylvania Department of Health Special Pharmaceutical Benefits Program (SPBP) and the HRSA Minority AIDS Initiative to work with 20 AIDS Service Organizations across Pennsylvania to implement a collaborative initiative to engage high-risk and lost-to-care HIV-positive clients in medical care.

The goal of MAI was to ensure that people living with HIV receive regular outpatient health care. Most challenging was locating those who were “lost to care” — patients who knew they were HIV positive, but who were no longer receiving regular, HIV primary care.

Drawing on his years of frontline experience, Smith asserts that, “We knew that the ‘lost to care’ population was sort of untouched, it would be a good population on which to focus. And we realized that the only way we could do that under federal requirements was through outreach.”

The ASOs that have been a part of this initiative (see Table) provide targeted outreach services to identify and link high-risk and lost-to-care HIV-positive clients to medical care with the aim of reducing the community viral load.¹⁸ They served different geographic areas and different population groups, including the LGBT community, behaviorally-infected adolescents (as opposed to those who were infected before birth) and those with pediatric HIV, IV drug users, and prison inmates. Their services ranged from clinical services to needle exchanges to innovative housing models, case management, and multidisciplinary care.

As part of the project, the ASOs attended a Lean-based quality improvement training and coaching program developed by PRHI. The method, called Perfecting Patient CareSM, enabled the ASO staff to learn and then use proven methods and tools to engage in continuous quality improvement.

Although the end goal for the MAI ASOs was reaching people living with HIV and keeping them in medical care, each ASO used the training differently, in accordance with their organization’s culture and their clients’ needs and preferences. Philadelphia-based Bebash, for example, used its PPC training to reduce time spent on paperwork and increase face-to-face time with clients. They designed a new process that reduced time spent on documentation by 40 percent

“That was a huge win for the care managers,” says JHF Senior Quality Improvement Specialist Stacie Amorose. “It saves hours of time each day, and it allows them to see more patients. One of the biggest dilemmas in Philadelphia is that there are a large number of HIV-positive patients on the waiting list for care management services. If we can

PENNSYLVANIA MINORITY AIDS INITIATIVE SITES

In April 2012, JHF received \$1.2 million in Minority AIDS Initiative (MAI) funding from the Pennsylvania Department of Health Special Pharmaceutical Benefits Program (SPBP) and the HRSA Minority AIDS Initiative to work with 20 AIDS Service Organizations across Pennsylvania.



Clarion

Northwest PA AIDS Alliance

Harrisburg

Hamilton Health Center
Pinnacle Health REACH Program*

Johnstown

Community Care Management (CCM)

Pittsburgh

Macedonia Family and Community
Enrichment Center (F.A.C.E.)
Pittsburgh AIDS Task Force (PATF)
Positive Health Clinic,
Allegheny Health Network
The Open Door, Inc.
Mon Yough Community Services*

Philadelphia

ActionAIDS
Bebashi Transition to Hope
Congreso de Latinos Unidos, Inc.
Mazzoni Center
Prevention Point Philadelphia
St. Christopher's Hospital for
Children - The Dorothy Mann
Center for Pediatric and
Adolescent HIV
Albert Einstein Medical Center
Immunodeficiency Center*
Philadelphia FIGHT*
Family Planning Council*

Reading

Co-County Wellness Services

Williamsport

AIDS Resource Alliance

* Phase II Grantees (July 2013 - June 2015).
Grant period for all others (Phase I) is
July 2012 - June 2014.

help care managers work more efficiently, then we can help more people with HIV get the services they desperately need.”

Bebashi also developed a standard work process for identifying, contacting, scheduling, and following up with clients. Bebash reviews client referrals from case managers and physicians daily. At least once a month, they review closed cases for clients who fell out of contact to identify patients at a high risk for being lost to care. They then implemented a very systematic process for making multiple contact attempts with these clients. Help with making and keeping appointments is also critical to keeping people in care. Bebash instituted an appointment reminder process, provided transportation to the appointment if needed, and even offered to accompany clients to the medical appointment itself.

Similar improvement processes were also put in place at Mazzoni Center (Philadelphia), Mon Yough Community Services (McKeesport), Pinnacle Health Resource Education and Comprehensive Care for HIV (Harrisburg), Albert Einstein Medical Center (Philadelphia), and Philadelphia FIGHT. Collectively, the goal of teaching and practicing these quality improvement methods and strategies is to enable the ASOs to better serve their community and clients.

“We learned that it’s not about case management; it’s about linking and bridging care between the client and the medical provider...”

—RICHARD SMITH

“AIDS Service Organizations can keep standard work processes like these in place at all times so that patients never fall out of care,” Amorose says. “It helps make the work done during MAI sustainable, rather than being a point-in-time project to bring people into care.”

The ASOs also learned to employ *motivational interviewing* (MI), a particularly patient-centered approach to encouraging goal setting and attainment. MI emphasizes the importance of understanding the patient’s perspective and feelings, eliciting their own reasons for change, and empowering patients to participate actively in making the best decisions about their health and treatment. MI teaches empathy, partnership, evocation, and respect for autonomy via face-to-face training, webinars, and onsite coaching. ASOs have adapted the method for use over the phone, as well as in print and social media communications

Others engaged in creative outreach. For example, Congreso, a Philadelphia-based organization providing services to the Latin American Community, identified a temporary heroin camp and established a rapport with those in need of medical care.

“They were able to build trust at this camp and say, ‘Hey, we’re not here to call the police or get you in trouble, but we do want to find out if you need health services,’” Amorose says. “Congreso took its mobile van and transported people to a medical clinic to get checked out. Establishing a good relationship opened the door for them to seek further care in the future.”

Finally, the ASOs met the challenge of tracking patients. With funding from the MAI grant, they were able to develop the human resources and data tracking capabilities needed to do this effectively. Monthly data sheets are completed by each MAI site, capturing 26 data points such as viral load, appointment dates, and general demographics.

"The data," says Program Director Richard Smith, "are being used to 'hot spot,' or identify, patients with high viral loads so that the MAI agency staff can step up outreach efforts to these specific patients. In addition, we are tracking the community viral load and thus able to measure the impact that MAI is having over time."

"At 18 months into the MAI project," continues Smith, "we've surpassed our patient enrollment goal by more than 56 percent and, of the clients who attended three medical visits, total viral load has fallen by 85 percent."

"A year and a half into the project [which will continue at least through June 2015], we've really been able to reach this population that was untouchable before, as there was no way of knowing or measuring whether we were reaching them. We did this by redefining outreach. We learned that it's not about case management; it's about linking and bridging care between the client and the medical provider, using motivational interviewing techniques."



**HOW
THE
WORLD
HAS
CHANGED**



REFLECTIONS ON THE EPIDEMIC’S IMPACT

The AIDS epidemic is not over. In the U.S. alone, approximately 50,000 people are newly diagnosed each year. In the Pittsburgh region, there is evidence that rates of transmission have been steadily increasing since 2006.¹⁹ Nevertheless, we can stop and assess what we’ve learned in the past 30 years.

Reflecting on the span of the whole epidemic, Karen Feinstein, president and CEO of the Jewish Healthcare Foundation, maintains that, “The fact that AIDS migrated from a death sentence to a chronic disease is testament to the efforts of the passionate activists who put the heat on the research establishment, the federal government, the media, the general public, and the pharmaceutical industry until they got the discovery that they sought.”

“A change that HIV brought with it was to move bureaucracies and to create strong advocacy groups”

— WARD CATES JR., MD, MPH

Perhaps more than achieving the discovery of life-saving medications, however, the activists — first in the gay community, but later buttressed by Americans from all communities and walks of life — changed, in Ward Cates’s words, “the face of public health.” As we explore below — in the words of several of those we interviewed for this Report — the world of public health was truly transformed, adopting the strategies employed by AIDS activists, integrating the lessons learned from the early years of the epidemic, and informing health education dialogue and communication on every level.

COMMUNITY ADVOCACY: EMPLOYING THE STRATEGIES USED BY AIDS ACTIVISTS

AIDS activists, in their demands and their protests and in vocalizing their needs, set the precedent for today’s consumer-oriented health advocacy groups. Breast cancer groups learned from ACT UP. In fact, all of the disease foundations get attention for their causes using what we learned as a result of advocacy during the AIDS epidemic. Nobody did that before gay men did it around HIV. They set the precedent for what’s possible. — Barb Feige, manager of the JHF fiscal agency 1995–2002



Ward Cates

Prior to HIV, the FDA had been a large monolithic organization which represented many of the worst aspects of bureaucracy when it came to the approval of new drugs. A lot of that was the heritage of thalidomide (the drug given for pregnancy morning sickness), which led the FDA to a swing on the pendulum towards cautious approval until a multitude of safety tests had been done. But for people with life-threatening illnesses like HIV — particularly when a whole variety of drugs became available in the late 1980s — beginning with AZT in 1987 — the strong in-your-face AIDS advocacy groups at the time protested in some very creative ways at the FDA, and then at the CDC until they got it right. — Ward Cates Jr., MD, MPHs

A change that HIV brought with it was to move bureaucracies and to create strong advocacy groups that would mobilize both the executive branch (like the FDA and CDC), but also the whole legislative branch. The whole HIV lobbying force was followed later by the breast cancer lobbying force, by the chronic fatigue lobbying force, by the you-name-it-lobbying force, for their particular diseases. — Cates

HEALTHCARE SERVICES PLANNING: COMMUNITIES SHAPING HEALTH AGENDAS

It started with organizing around HIV, but now community action in health matters has become a partnership with health departments. Rather than health departments, somewhat paternalistically, providing services that the health departments think that their communities want, we are now more likely to see health departments asking communities to help identify their own high priority needs and solutions. I see HIV as being pioneering in offering that opportunity to the community. — Cates

HEALTH COMMUNICATION: FROM SEX EDUCATION TO SEXUAL HEALTH

Over the course of the 1980s, there were major changes with regard to how our society handled matters of sexual or reproductive health. By 1990 when you went into the drug store, unlike when I was growing up, condoms could be purchased in the main aisles and cigarettes were behind the counter! There was a whole switch in terms of our prevention priorities. — Cates

The fact that condom use is now a given comes from the transmission of HIV. It comes from gay men getting together and giving out free condoms in the baths, in the bars. The idea of safe sex spread to the heterosexual community. Now it's such a given that they are advertised on TV and that has reduced other sexually transmitted infections as well as unplanned pregnancies. — Feige

The HIV epidemic also encouraged a healthy discussion on the content of sex education. We went from VD movies in gym class to life planning classes that include sexuality planning classes, offered in age-appropriate ways in school. The whole field of sexuality and sexual topics has become much more open, which in my value system is a good thing, regardless of what personal choices you make.— Cates

“We are all one nation under health threats”

Reflecting on the lessons gleaned from the epidemic, Feinstein suggests that, “Most of all, I think that we learned that we are all ‘one nation under health threats’ and that blaming, isolating, ignoring, or dismissing any segment of our population creates a serious health threat to all.”

“We also learned that, despite differences, we really are one community. The poignant stories of loving and courageous parents and partners supporting victims helped to humanize the face of homosexuality in ways that have surely contributed to a more tolerant, open, and even creative world.”

These stories were conveyed in an explosion of artistic forms, from theatre (*The Normal Heart* by Larry Kramer) to film (*Rent* by Jonathan Larson) to pop art (Keith Haring’s AIDS art) to folk art (the AIDS Memorial Quilt conceived by Cleve Jones). Across the U.S., voters, bureaucrats, insurers, and health professionals had to realize and act on their beliefs that *all* citizens are entitled to excellent and sympathetic health care, coverage of their health costs, and supportive services.

Says Feinstein, “May there never be another epidemic to which we have to apply these lessons, but paradoxically, there is no question that the U.S. is a better place, and that we are a better people, as a result of the ways in which communities responded to the challenges of the AIDS epidemic.”

“We learned that we are all ‘one nation under health threats’ and that blaming, isolating, ignoring, or dismissing any segment of our population creates a serious health threat to all.”

— KAREN WOLK FEINSTEIN, PHD



BE
THE
GENERATION

Marchers rallied December 2, 2012 to observe World AIDS Day. Researchers are still battling the disease, and the stigma that comes along with it.



BIOGRAPHICAL SKETCHES OF INTERVIEWEES

Ward Cates Jr., MD, MPH, has 40-plus years of experience in the fields of women's health, prevention of sexually transmitted infections and HIV, contraceptive technology, and reproductive health services. During his 20-year tenure at the Centers for Disease Control and Prevention (CDC), Dr. Cates served in various roles including chief of the Abortion Surveillance Branch in the Family Planning Division, director of STD/HIV Prevention, and director of the Division of Training in the Epidemiology Program Office. He is president emeritus of FHI 360, one of the largest and most active nonprofit organizations in human development with field activities in more than 70 countries. He has overseen a robust program in microbicide and HIV prevention research at FHI 360, serving as co-principal investigator or principal investigator of several major multi-million dollar grants. Dr. Cates is also an adjunct professor of epidemiology at the University of North Carolina, Emory University, and the University of Michigan's School of Public Health. He received his MD and MPH from Yale and is board certified in general preventive medicine with a specialty in epidemiology.

Anthony Silvestre, PhD, LSW, was hired as the director of community programs for the Pitt Men's Study in 1984. In that position, he recruited more than 3,000 local gay and bisexual men into the study and began publishing research findings dealing with HIV education and prevention. Dr. Silvestre now leads recruitment and retention efforts and a number of behavioral initiatives for the study. As a founder of the former Center for Research on Health and Sexual Orientation, he is working to bring together a multi-discipline faculty to collaborate as researchers and teachers in the field. Dr. Silvestre also directs the HIV Prevention and Care Project at the University of Pittsburgh. The project, contracted through the PA Department of Health, facilitates HIV care and prevention planning in the state. Dr. Silvestre received his PhD in social work from the University of Pittsburgh.

Michael Seltzer is a co-founder and former executive director of Funders Concerned About AIDS, a coalition of private philanthropic organizations advocating for increased, targeted HIV/AIDS funding. Mr. Seltzer is also a distinguished lecturer in the School of Public Affairs at Baruch College. Previously, he served as a program officer at the Ford Foundation and president of Philanthropy New York, a consortium of private, family, corporate, and public foundations that supports nonprofits and non-government organizations both locally and globally. Mr. Seltzer received his bachelor's degree in international relations from Syracuse University.

Jim Huggins, PhD, is a licensed psychologist and a sex therapist certified by the American Association of Sexuality Educators, Counselors and Therapists (AASECT). Dr. Huggins is the co-founder and previous associate executive director of PERSAD Center, a mental health center for sexual minorities. He retired from PERSAD after nearly 30 years of service in 2001. Dr. Huggins has published numerous articles and chapters and conducted workshops and seminars, both locally and nationally, which address the psychosocial and mental health issues of sexual minorities and people living with HIV. He currently maintains a full-time private practice in Shadyside. Dr. Huggins obtained his master's degree from West Virginia University and his PhD from the University of Pittsburgh.

Dana Phillips came to Pittsburgh from Chicago, initially working as a program officer for The Pittsburgh Foundation. Ms. Phillips has 13 years of experience in correctional health care administration as the COO and then CEO of Allegheny Correctional Health Services, Inc., providing health services to the county jail; and more than twenty years of general health care administrative experience. She was one of the founders and the original chair of the Southwestern Pennsylvania AIDS Planning Coalition, was active in starting other similar planning coalitions across Pennsylvania, and served on the statewide HIV Planning Council. She served as an adjunct faculty member at the H. John Heinz III School of Public Policy and Management at Carnegie Mellon University for 20 years and on the faculty of several other universities. She has served as a consultant to nonprofit organizations in the areas of financial management and planning; marketing; strategic planning; and board, organizational and resource development. Ms. Phillips received her master's degree in Speech Pathology from the University of Michigan and a master's degree in Management from Northwestern University.

Karen Wolk Feinstein, PhD, is president and CEO of the Jewish Healthcare Foundation and its two operating arms, the Pittsburgh Regional Health Initiative and Health Careers Futures. Appointed the Foundation's first CEO in 1990, she initially focused on health issues endemic to aging, women's health, and underserved populations. She has since made JHF and PRHI a leading voice in patient safety, healthcare quality, and workforce issues. When Dr. Feinstein founded PRHI, it was among the nation's first regional multi-stakeholder quality coalitions devoted simultaneously to advancing efficiency, best practices, and safety in health care through the use of industrial engineering principles. Dr. Feinstein also founded Health Careers Futures to assist the region's healthcare industry in attracting, preparing, and retaining employees, and was a leader in the formation of the Network for Regional Healthcare Improvement (NRHI), a national coalition of Regional Health Improvement Collaboratives that supports national policy efforts to improve healthcare quality and value. Dr. Feinstein has previously held executive posts at other nonprofits, including United Way, and is a past president of Grantmakers In Health. She serves on a number of nonprofit and for-profit boards, including the board of directors of NRHI, the Center for Innovation Advisory Committee at the National Board of Medical Examiners, the board of overseers at Brandeis University's Heller School, and as co-chair of the board of directors for the Pennsylvania Health Funders Collaborative.

Barb Feige joined the ACLU-PA as Pittsburgh Chapter Director and statewide Associate Director in 2002. She was named Deputy Director for the statewide organization in 2008. In addition to financial oversight, policy development, and Board administration, Ms. Feige is responsible for all of the non-legal activities of the Western PA office such as membership, development, and oversees public education efforts. Barb is an experienced non-profit manager with over 25 years' experience. Prior to joining the ACLU-PA, she served as the HIV/AIDS program manager for the Jewish Healthcare Foundation of Pittsburgh providing fiscal management and programmatic support to government-funded services for persons affected by and at risk for HIV/AIDS. Barb has also worked for the United Jewish Federation of Greater Pittsburgh as Community Campaigns Coordinator involved in all aspects of fundraising. A Pittsburgh native, Barb is a magna cum laude graduate of Duquesne University and did her graduate work at the University of Pittsburgh. Barb is an active community volunteer and serves on the boards of a number of community service organizations.

Jason Kunzman is the director of Account Management with RxAnte, a company based in McLean, VA that uses predictive analytics and an integrated decision support engine to improve patient outcomes and reduce overall costs through better medication use. Prior to joining RxAnte, Mr. Kunzman was the Deputy Director for the Office of the National Coordinator's Beacon Community Program where he had a significant role in shaping strategy with local stakeholders in regions across the U.S., with a focus on integrating measurement, quality improvement, IT, consumer engagement, and novel approaches to payment. Prior to his work at ONC, he spent eight years as the CFO/COO for the Jewish Healthcare Foundation. In addition to managing the Ryan White HIV/AIDS fiscal agency for the Foundation, Mr. Kunzman helped lead a number of healthcare quality improvement projects targeting preventable medical errors and waste while lowering the overall cost of care. A criminology major, Mr. Kunzman holds a BA from the University of South Florida and an MBA from the University of Baltimore. He is also a Certified Public Accountant.

Richard Smith, MSW, serves as the HIV/AIDS program director. Mr. Smith has extensive experience in quality management, having served as the continuous quality improvement coordinator for Albert Einstein Medical Center HIV Clinic in Philadelphia, committee member of the HRSA Collaborative, and a member of the HIV National Quality Program. He has completed several National Quality Center trainings on quality management and holds a mental health counseling background as a therapist and social worker. Mr. Smith earned his bachelor's degree in psychology from Lock Haven University and a master's degree in social work from the University of Pittsburgh.

Caroline Acker, PhD, is a historian of medicine and public health whose research has focused on medical and scientific ideas about opiate addiction in the U.S. since about 1890. She came to this academic interest from her former work as director of a community-based drug information agency in Miami, Florida. She held the first DeWitt Stetten, Jr. Memorial Fellowship in the History of Twentieth-Century Biomedical Sciences and/or Technology at the National Institutes of Health from 1993–1994. Her book, *Creating the American Junkie: Addiction Research in the Classic Era of Narcotic Control*, weaves the experience of addicts with the efforts of researchers to understand addiction in the period when the American policy of drug prohibition was being established. She is also interested in the intersection between AIDS and drug policy. Through her work with Prevention Point Pittsburgh, a local harm reduction and needle exchange program, she has helped broaden the range of HIV prevention services available to injection drug users and increase local policy awareness of the health needs of this population. Dr. Acker received her PhD from the University of California, San Francisco.

Marni Vliet is a consultant to non-profit and for-profit organizations across the country in the areas of strategic planning and communication, organizational development, governance, health programming, and health policy development. She formerly served as president and CEO of the Kansas Health Foundation, which promotes wellness through the program areas of civic leadership, community philanthropy, health data and information, and public health. Ms. Vliet is a member of Funders Concerned About AIDS and a former board chair of Grantmakers in Health and the Community Anti-Drug Coalitions of America. She also has been a member of the boards of directors for the CDC Foundation and Drug Strategies, served on the health promotion advisory board of the Kaiser Family Foundation, and was the founding chair of Funders Against Substance Abuse. Ms. Vliet received her master's degree in health education from Wichita State University.

Pamela Vingle is a former project manager for the Jewish Healthcare Foundation with over 40 years of experience in Pennsylvania's nonprofit community. Ms. Vingle has worked as a hospital case manager, counselor to female offenders, and a work release center supervisor. She was also among the first staff members of the Pittsburgh AIDS Task Force, serving as director of volunteers. While at the United Way of Pittsburgh, Ms. Vingle staffed the Health and Wellness and Aging projects and was the Goal Area Specialist. Ms. Vingle received her bachelor's degree in social work from Fairmont State University.

Keith Kanel, MD, is the chief medical officer for the Jewish Healthcare Foundation and its supporting organizations, with primary responsibility for such projects as the Primary Care Resource Center initiative. He is an internal medicine physician with over 20 years of clinical and administrative experience in prominent academic medical centers and progressive integrated delivery systems. He was previously chief of General Internal Medicine at Allegheny General Hospital, where he co-founded one of the region's first hospitalist services and was director of its primary care training program. He has served on the faculties of the University of Pittsburgh School of Medicine, the Drexel University College of Medicine, and the Carnegie Mellon University H. John Heinz III School of Public Policy and Management. Dr. Kanel is the author of multiple articles and textbook chapters on topics ranging from patient safety to electronic health information technology. His focus areas include quality improvement, health delivery systems, and payment policy. He received his MD from the University of Pittsburgh and his MHCM from Harvard University.

Stacie Amorose is a senior quality improvement specialist for the Pittsburgh Regional Health Initiative (PRHI). In this role, she works with clients in a variety of healthcare settings to implement strategies that eliminate waste and improve efficiency. She is responsible for reviewing, teaching and implementing Perfecting Patient CareSM curriculum for Jewish Healthcare Foundation (JHF) and PRHI clients. Her current roles include project management and implementation of our PPC strategies in JHF's Minority Aids Initiative. Ms. Amorose earned her bachelor's degree in public service administration from Waynesburg University.

ORGANIZATIONS FUNDED VIA THE JEWISH HEALTHCARE FOUNDATION

through June 2014

From its inception, JHF, through its own endowment, has supported more than \$850,000 in programs that educate, train, inform, direct, recommend and take actions to improve the response to the HIV epidemic and to care for those infected in southwestern Pennsylvania, successfully leveraging JHF relationships and efforts toward assuming the additional roles of planning and evaluation.

EFFORTS IN THE AREA OF PREVENTION

Minority Prevention/Education Program — Pittsburgh AIDS Task Force (1991) \$37,000

An outreach and information campaign targeting African-American communities, with culturally appropriate materials and information, was undertaken to help prevent the spread of HIV among those who are disproportionately represented in AIDS cases.

Adolescent Resource Network — Family Health Council (Adagio) (1992) \$78,000

To help prevent teen pregnancy as well as HIV/AIDS, the Foundation worked with the Adolescent Resource network, a peer health-education effort, to improve the effectiveness of education programs and campaigns.

AIDS Awareness for Youth — Rotary Club of Pittsburgh (1992) \$12,000

A unique partnership between the Rotary and Pittsburgh Public Schools produced a peer education program for AIDS awareness and avoidance skills among high school and middle school students.

Prevention Point Pittsburgh (1997) \$30,000

Working with a non-profit that provides health empowerment services to injection drug users, JHF implemented an evidence-based model to reduce the transmission of HIV in a notoriously difficult to reach population.

Readmissions Reduction — Allegheny General Positive Health Clinic (2011-2012) \$150,000

With matching funds from The Pittsburgh Foundation and the JHF endowment, JHF worked with a local AIDS service organization, the Positive Health Clinic, to improve the quality of care, lower costs, and reduce avoidable readmissions for HIV-positive patients. The initiative resulted in a 52 percent reduction in hospital readmissions for their HIV-positive patients.

COMMUNITY INITIATIVES

Southwestern Pennsylvania AIDS Action Plan (1992-1993)

\$109,000

The Foundation convened and coordinated the work of a community advisory committee (made up of foundations, funders, and health and social service organizations) to review existing information, develop additional information, and draft an *AIDS Action Plan* that set the direction for a comprehensive response to the HIV epidemic in our area.

Regional Needs Assessment — Pittsburgh AIDS Task Force (2002 / 2007)

2002: \$30,000

2007: \$25,000

In order to help address a serious deficiency in the availability of qualitative information documenting the unmet need of the HIV positive population in southwestern Pennsylvania, JHF funded the Pittsburgh AIDS Task Force and the University of Pittsburgh Graduate School of Public Health to conduct a regional needs assessment. In addition to developing a better understanding of the needs of those living with HIV in our region, the goals of the needs assessment were to determine what barriers prevent clients from accessing care, to restructure agency programs and processes to improve service delivery, and to create a process of successfully engaging and surveying individuals living with HIV/AIDS from a variety of backgrounds.

HIV Quality Management Web Portal (2008)

In-Kind

JHF successfully funded a pilot project in quality management that uses an innovative information technology platform allowing participating AIDS service organizations to view how they are performing against predetermined quality indicators and immediately connect to CME/CE-certified activities designed to drive improved performance with respect to each of the quality indicators. This project is supported by the Pennsylvania Department of Health and is being used to provide data for a multi-site HRSA Quality Management collaborative.

Capacity Building Consultant for Minority Agencies — Six Provider Sites (2011-2012)

\$21,000

JHF funded a private consultant company to help minority agencies in the region to increase capacity in relation to board development, fiscal capability, and administrative support. Providers developed work and strategic plans with consultants to assist their agency with professional growth.

COMMUNITY EDUCATION

Education and Training on Sexual Minorities – Persad Center, Inc. (1993)

\$50,000

JHF supported a three-year educational outreach effort providing diversity training for counselors, teachers, youth workers, and employers to increase their awareness regarding gay youth. The program also conducted AIDS education programs for major corporations.

Consortium Ethics Program – Center for Medical Ethics (1993)	\$15,000
Area physicians and healthcare providers developed a forum for discussion of the new ethical issues arising from the AIDS epidemic.	
AIDS Interfaith Care Teams — Christian Associates (1994)	\$30,000
Union of American Hebrew Organizations – AIDS Awareness (1994)	\$5,000
AIDS Care Team — Christian Associates (2004)	\$15,000
Perfecting Patient Care (2005/2006)	In-Kind
JHF provided local AIDS service organizations with a four-module training course designed to provide the building blocks by which frontline staff could begin to identify root causes of error and waste across systems and programs; and institute corrective measures that ultimately improve the services delivered to the consumer.	
Serial Passage – HIV/AIDS Documentary (2006)	\$25,000

DEVELOPING A CONTINUUM OF CARE

A Personal Care Home – Verona House Corporation (1993/1994)	\$60,000
A major service gap identified by the Foundation’s <i>AIDS Action Plan</i> was the lack of a personal-care home targeted for younger HIV-positive adults and linked to a continuum of services for people with AIDS. The Foundation support enabled Verona House to begin providing care in its 23-room facility.	
An Incentive Grant to Strengthen Health Partnerships (1995)	\$50,000
A partnership of the Pittsburgh AIDS Task Force, Persad Center, Shepherd Wellness Community, Verona House Corporation, and the Pittsburgh AIDS Center for Treatment received an incentive grant to prepare a strategic plan for the integration of AIDS services in the local area. The intent of this partnership was to plan for a full continuum of services and position providers to better deal with the changing environment of healthcare reimbursements.	
PATF – Targeted Case Management (1995)	\$35,000
PATF – Using Volunteers to Improve Medical Compliance (1999)	\$50,000
Supportive Services for Homeless Persons with HIV/AIDS – The Open Door (2007)	\$25,000
Recognizing that homeless people living with HIV have poorer health than people living with HIV in stable housing, the Foundation provided funding to The Open Door, allowing its residents to take a more active approach in their own HIV clinical care processes.	

ENDNOTES

- ¹ Gould, RE, "Reassuring News About AIDS: A Doctor Tells Why You May Not Be At Risk," *Cosmopolitan*, January 1988.
- ² The Foundation for AIDS Research (Amfar), "Thirty Years of HIV/AIDS: Snapshots of an Epidemic," www.amfar.org/thirty-years-of-hiv/aids-snapshots-of-an-epidemic/, accessed June 16, 2014.
- ³ For example, in 1983, the New York Funeral Directors Association urged members to not embalm AIDS fatalities. *New York Magazine*, "AIDS in New York: A Biography," 2006. <http://nymag.com/news/features/17158/>, accessed June 16, 2014.
- ⁴ This section draws on an excellent *New York Magazine* article published June 5, 2006: "AIDS in New York: A Biography," <http://nymag.com/news/features/17158/> accessed June 5, 2014.
- ⁵ AIDS Action Plan, A Community Commitment, Jewish Healthcare Foundation, 1992.
- ⁶ Centers for Disease Control and Prevention. Mortality Attributable to HIV Infection Among Persons Aged 25–44 Years — United States, 1994. *MMWR Weekly* 45(06): 121–125, February 16, 1996. www.cdc.gov/mmwr/preview/mmwrhtml/00040227.htm, accessed June 16, 2014.
- ⁷ Op cit., *New York Magazine*, 2006.
- ⁸ Op cit., *New York Magazine*, 2006.
- ⁹ National Minority AIDS Council, *African Americans, Health Disparities and HIV/AIDS*, November 2006. http://img.thebody.com/nmac/blacks_aids.pdf, accessed June 16, 2014.
- ¹⁰ Rudnick, Mark, "Prevention Point Pittsburgh: A Public Health Initiative and its Local Impact," Carnegie Mellon University, April 29, 2009, page 4, accessed June 16, 2014.
- ¹¹ Vlahov D and Junge B, "The role of needle exchange programs in HIV prevention," *Public Health Rep.* Jun 1998; 113(Suppl 1): 75–80. www.ncbi.nlm.nih.gov/pmc/articles/PMC1307729/?tool=pubmed, accessed June 16, 2014.
- ¹² Centers for Disease Control and Prevention, Today's HIV/AIDS Epidemic, page 3 chart. www.cdc.gov/nchhstp/newsroom/docs/hivfactsheets/todaysepidemic-508.pdf, accessed June 16, 2014.
- ¹³ Kanel KT, Elster S, Vrbin C, "PRHI Readmission Brief: Using Hospital Admission and Readmission Patterns to Improve Outreach to Persons Living with HIV/AIDS in Pennsylvania," July 2010. An update of the study published in 2012, and a statewide study are available on the PRHI website. www.prhi.org/newspublications?task=sub&cat=7, accessed June 16, 2014.
- ¹⁴ Centers for Disease Control and Prevention, "HIV in the United States: At A Glance," November 2013. www.cdc.gov/hiv/pdf/statistics_basics_factsheet.pdf, accessed June 16, 2014.
- ¹⁵ Centers for Disease Control and Prevention. *Linkage to and retention in HIV Medical Care*. 2012. Available at www.cdc.gov/hiv/prevention/programs/pwp/linkage.html, accessed June 16, 2014.

- ¹⁶ Pennsylvania Department of Health, "The Continuum of Engagement in HIV Prevention/Care," Presented at Pennsylvania State HIV Capacity Building Meeting, State College, PA, 2013; and Gardner EM, McLees MP, Steiner JF, delRio C & Burman WJ, "The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection," *Clinical Infectious Diseases* 52(6): 793-800, 2011.
- ¹⁷ Centers for Disease Control and Prevention, "HIV in the United States: Stages of Care. July 2012. www.cdc.gov/hiv/pdf/research_mmp_StagesofCare.pdf, accessed June 16, 2014.
- ¹⁸ Community viral load is a measure is a measure of the amount of the HIV virus (an indicator of the severity of the infection) across all HIV-positive individuals in a given area.
- ¹⁹ PA Department of Health, HIV Epidemiology Investigation Section, Bureau of Epidemiology, APPENDIX: INTEGRATED EPIDEMIOLOGIC PROFILE OF HIV/AIDS IN PENNSYLVANIA, 2012-13. APPENDICES

ACKNOWLEDGEMENTS

The writers of this *Roots*, Susan Elster and David Golebiewski, express their appreciation to all who shared their voices and their reflections in telling this story. We also acknowledge with appreciation and even awe, the countless volunteers and professionals, people living with HIV and their loved ones, who demonstrated the best of what it means to be human amidst terrible suffering and isolation.

WRITING

Susan Elster and David Golebiewski

DESIGN

Landesberg Design, Pittsburgh PA

PHOTOGRAPHY

Joyce Mendelsohn, *Pittsburgh Post-Gazette*, page 27

Jeff Swensen, Getty Images, pages 28–29

Leigh Meryhew, page 39

Ohad Cadji, pages 44–45

Printed on FSC-certified Domtar Cougar
(10% post-consumer reclaimed fiber)



Centre City Tower, Suite 2400
650 Smithfield Street
Pittsburgh, PA 15222
412-594-2550
info@jhf.org / www.jhf.org

ROOTS is a special publication of the Jewish Healthcare Foundation and its supporting organizations.