'It's the greatest living experiment': Pitt Men's Study marks 40 years of AIDS research

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In a Pittsburgh hospital in the early 1980s, Charles Rinaldo saw a young, previously healthy gay man critically ill with a virus usually only seen in weakened immune systems.

Around the same time, Jeffrey Toth was hearing terms like "the gay cancer" and "gay related immune deficiency"—and watching players in his gay softball league get mysteriously ill.

"People were dying and we didn't know why," said Marc C. E. Wagner. "I knew it was a devastating condition, even early on."

Through gay bars and picnics, word began to spread about a study at the University of Pittsburgh investigating the disease, and on April 1, 1984, the study officially began recruiting its first participants.

Forty years later, the Pitt Men's Study is one of the longest-running studies on HIV and AIDS in the country. About 2,000 men have participated since the beginning, coming every six months to give blood samples and answer questionnaires, building a scientific goldmine in the process.

"It's the greatest living experiment," said Wagner, an AIDS researcher at Pitt and one of the original study participants. "As one of my mentors, who is no longer with us, once told me, "You start in ignorance and you grow in knowledge, and that's the basis of science.'"

Overall, 1,811 people have participated in the Pitt Men's Study over the last 40 years, with 438 still-active participants—201 of those who joined in 1985 or before. Of those who have ever participated in the study, 539 have died from AIDS or other causes.

In 1978, Rinaldo came to Pittsburgh, fresh from completing postdoctoral studies at Massachusetts General Hospital in Boston. His focus was an "opportunistic virus" called cytomegalovirus that attacked people with weakened immune systems, such as organ transplant recipients. Pittsburgh was growing as a transplant center by 1981, boosted by the arrival of transplant pioneer Thomas Starzl.

That same year, Rinaldo remembers seeing a "perplexing case" of a critically ill gay man in his mid-20s with CMV and Pneumocystis pneumonia, another opportunistic virus. Unlike most of the patients that Rinaldo saw with CMV, he had no previous health problems and had not received an organ transplant. Though the disease didn't have a name yet, the man is now recognized as Pittsburgh's first known AIDS patient, and later died of the disease.

Shortly afterward, Rinaldo met David Lyter, a Pitt medical student who had recently come out as gay. Lyter had seen the new disease affecting the gay community and approached Rinaldo about putting together a study to investigate it. With no official funding, and with Lyter doing most of the recruiting, they put together a pilot study of about 70 gay men.

At the same time, the country was starting to recognize the virus as well. In June of 1981, the U.S. Centers for Disease Control reported on a cluster of five cases in Los Angeles—all gay men with no known contact with each other, sick with Pneumocystis pneumonia and CMV infections. In September 1982, the CDC used the term AIDS, or acquired immune deficiency syndrome, for the first time. A few months later, the National Institutes of Health put out a request for research proposals for a large study of the new disease.

The study was looking to include one research site in a city that didn't have as high of an incidence of AIDS as major population centers such as L.A. or New York City. "They thought maybe there was a different cause," said Rinaldo. "That was one of the hypotheses at the time."

Rinaldo was decades younger than most of the academic heavyweights vying for funding. But with the support of leaders at the university, he applied.

In the summer of 1983, he received a grant for $4.2 million—which equates to more than $13 million in 2024—over four years. The study, called the Multicenter AIDS Cohort Study, also included sites in San Francisco, Los Angeles, Baltimore and Chicago, and all except San Francisco are still involved today.

"We were to define the natural history of what was just then being called AIDS," said Rinaldo. "We did not know the virus that was the cause of this. Part of our intent was to help discover what was causing this mysterious disease."

But first, Rinaldo needed to find more than 1,000 gay men to come to Pittsburgh to participate in the study—at a time of great fear of the virus and stigma toward homosexuality.

Building the study

"I'm a straight male scientist, never having dealt with the LGBTQ community," he said. "This is Pittsburgh; it wasn't San Francisco. That community was not as prominent and accepted as it was in some of the larger cities at the time."

With Lyter's help, he enlisted the Tavern Guild—a group of gay bar and bathhouse owners—to spread the word. They recruited at gay bars, putting up posters and handing out napkins with the study's name and address. Sometimes they took blood specimens right in the bars, using an office or coat check room. Many bars at the time had switched to using plastic utensils, unsure how the virus could spread.

The study also hired Tony Silvestre, a prominent gay leader from Philadelphia, to lead recruiting. An instrumental part of the history of the Pitt Men's Study, Silvestre died in 2022.

The recruitment was effective, in part because some viewed it as their chance to do something positive about a terrible situation.

Toth heard about the study from a former boss. "HIV was affecting the community—nobody knew what it was, but it was quite scary back then," he said. "We were younger back then, and we saw some older people just getting very sick. We thought, 'Oh, we have to do something. It may affect us eventually.' And it did."

Because of the fear at the time, the study took immense precautions on secrecy. The clinic was in the Oakland neighborhood of Pittsburgh, not in a university building. Participants were identified only by an ID number; information about their names was kept in a different office in a different building.

Even outside of the building, employees of the study practiced strict confidentiality.

"If you were walking down the street and saw someone and you knew they were part of the study, you just walked right past them," said Bill Buchanan, who worked for the study from 1988 until he retired in 2022. "Unless you talked to me first, it would be like I never saw you in my life. You have to play that game."

Even the door to the clinic didn't fully identify what was going on. "There were no signs on the door that said Pitt Men's Study. It just said PMS Clinic," said Buchanan. "Once in a blue moon, you'd get a woman that came in. When she found out that wasn't what PMS meant, she'd get a little upset."

At first, visits to the clinic would involve taking all sorts of specimens—blood, saliva, feces, semen—and questionnaires about sexual practices.

"Back then, we took everything," said Rinaldo. "We didn't know what we were looking for."

Evolving testing

In 1985, the FDA approved a test to determine whether antibodies for the virus that caused AIDS were present in a blood test.

All these men who had submitted blood samples could now find out—if they chose to—whether or not they had the virus now known as HIV.

The researchers carefully developed a protocol for how they would let the participants know: They would tell them in person, whether they were positive or negative.

Wagner remembers going in for his session. Though he had no symptoms, he was told that his blood did have the antibodies. Sometime in between his first and second visit to the study, he contracted HIV.

"It was devastating," he said. "Back then, there were literally no medications. All you were hearing was that it was a death sentence—that in some course of time that you didn't know yet, you would die."

In Pittsburgh, about 22% of the participants had antibodies indicating HIV. In some of the other sites in the study, that figure was closer to 50%.

Testing for HIV and AIDS improved further with viral load testing, which not only showed antibodies but also the presence of the virus itself.

One of the Pitt Men's Study's most important findings was research on viral loads in the mid-1990s, showing that people who had higher levels

of the virus in their blood were much more likely to develop AIDS than people who had lower levels.

"Common sense would dictate it, but we were the first to actually prove it," said Rinaldo. "To this day, it's one of the most cited papers in the field."

Forging community

With so many gay men—both with AIDS and without—regularly visiting the Pitt Men's Study office, it started to become a de facto clearinghouse of information. Pittsburgh's gay infrastructure wasn't as developed as in cities with larger populations, such as San Francisco, and people weren't sure where else to turn.

"Ultimately, people would turn to the study for all kinds of help—medical help, legal help, I've been evicted from my apartment," said Buchanan. "We were a study, we didn't have those kinds of resources, and that was the impetus behind creating the Pittsburgh AIDS Task Force."

The study frequently referred those with AIDS to Jerry Rabinowitz, who was killed in the Squirrel Hill synagogue shooting in 2018. Rabinowitz was one of the first doctors in Pittsburgh willing to treat AIDS patients.

Contributing to the study's legacy are the larger AIDS services that developed from it. Education programs that stemmed from the study likely prevented many more AIDS cases, said Buchanan.

The study also created a community advisory board that continues to this day, and for years the study led the way locally in commemorating World AIDS Day in Pittsburgh.

Growing understanding—and options

As the AIDS epidemic continued, understanding of the virus grew, as did treatments. In 1987, the FDA approved the first AIDS drug, called AZT. The drug prolonged the lives of some AIDS patients but had serious side effects for some, such as nausea, liver problems and headaches.

For Wagner, the side effects of AZT were unbearable. In what he believed was a choice between quality of life and quantity of life, he stopped taking it.

By 1993, HIV was the leading cause of death among Americans aged 25 to 44. But new and better drugs were on the way. In the mid-1990s, the FDA approved combination therapies that were more effective, but required taking many pills per day. By the late 1990s, those medications were further improved and consolidated into fewer pills.

With medication, Wagner's viral load is now so low that it is considered undetectable. "I've outlived so many of my relatives. If you would have told me at the beginning of this journey that I would still be here and they would be gone, I never would have believed this to be possible. The study gave back to me so much understanding of my own body, peace of mind of knowing what's going on."

In some ways, the study has transformed into research on aging with HIV and AIDS, and the effect that the virus has on the body.

With such a large bank of data—and 40 years of specimens in freezers—there are unlimited opportunities for research. Rinaldo is involved in one study that has taken modern understanding of microbiomes and applied it to decades-old stool samples of HIV-positive men, showing differences in the bacteria of those who developed AIDS.

Other studies are looking at how HIV affects men who become infected today versus in the early 1980s.

"Forty years later, the specimens that the men gave us are extremely relevant," said Rinaldo. "I tell my students and postdocs, every time you go into the freezer and take out these specimens, just remember how we got these. Even with all the fancy technology we use now, there's no way at all we could do all this without these men."

And to those involved, the study has meant more than just science. For 40 years, they have come to a nondescript building, sharing not just their blood but also friendship, sorrow and camaraderie.

"It's one of the most dedicated groups of people that I've ever seen. Some of the best people in the world walk through that door," said Buchanan. "I came to love them as friends. Even though I'm retired, there's a number of them who said, 'I need your home number, I need to stay in touch.' Some of them showed up at my mother's funeral last month."

Part of the close kinship, of course, comes from tragedy. Toth, one of the original participants and a current data manager for the study, still has a photo from his gay softball team in the early 1980s. "The majority of the team is gone," he said, "and most of them, sadly, is because of AIDS."

Later this year, the study will hold events to honor the participants and mark 40 years.

"I don't call this a celebration: I call this a commemoration," said Rinaldo. "We won't be celebrating until we don't have to do this anymore—until we cure this infection or have a vaccine. We want to keep this going until the study is no longer needed."