

A Glimpse Inside the Life of an HIV Positive Columbian

By **BENJAMIN RYAN**

Spectator Contributing Writer

Steve is a talented, intelligent artist, in avid pursuit of a masters degree from Columbia's Graduate School of the Arts. He hangs out at Ollie's, shops at the West Side Market, works out in Dodge, and jogs in Riverside Park. He likes pop music, bookstores, and going to movies with friends. With only 27 years to his credit, he shares the youthful exuberance of the collegiate environment around him—facing the future with relentless drive.

Tall, lean, and stylish, Steve sports a navy V-neck top and faded blue jeans. The lights in his apartment are dimmed, casting soft shadows across his face. His eyes shine, revealing a gentle soul, and also sadness. He sits on the edge of his bed, and with a soft spoken, earnest demeanor, shares a less public part of his life:

Steve is HIV-positive.

He speaks candidly, but reveals his HIV status only under anonymity (Steve is not his real name). Other than a close circle of his friends and family, few share the knowledge that Steve is infected with the virus that causes AIDS. He says he keeps the secret to protect himself, not knowing whether he could handle the prejudices of public reaction.

"Oh, that's Steve and he's really talented ... and he has HIV," Steve stated rhetorically. "I'm not ready for that identity yet."

Steve feels he cannot trust his HIV-positive status with the Columbia community, which he feels is "a demographic of people who judgmentally are probably very ignorant."

He described the trouble he has skipping out of a late afternoon class, rushing to the bathroom to take his four o'clock dose without being seen.

"I just hate that moment of scooping up sink water. It just reinforces those negative affirmations," he said.

The fear of discovery has kept him from pursuing many personal and academic relationships. He shies away from approaching anyone in his department at Columbia for fear of having to disclose his status, which could open the floodgates of information to the rest of his peers.

"[HIV] takes a lot of romance out of things," he said. "I wonder about the reaction at the gym," he said, referring to the place on campus where he feels most vulnerable to the scrutiny of others.

He feels that if people knew about his status, they might feel uncomfortable using the same exercise equipment as he, coming in contact with his sweat, using the same showers.

HIV at Columbia in Context

Columbia's urban location is anything but disconnected from the presence of HIV and AIDS. According to the Center for Disease

Control, New York City has reported 101,670 cumulative cases of AIDS to date—nearly one-sixth of the nation wide total of 641,086 cases.

These statistics do not reflect the lesser known figures on those who are infected with HIV but have not yet developed AIDS. Current estimates place the national figure between 650,000 and 900,000 people, with about 40,000 new infections per year.

The Columbia University AIDS Memorial is an online listing of University affiliates who have died from complications with the disease. To date, the list consists of 121 names, which, according to the site, "surely reflects only a tiny percentage of Columbians overall who have died from the epidemic, which itself is only a tiny percentage of those worldwide who have died of AIDS."

An estimated 30.6 million people are currently living with HIV/AIDS worldwide. 11.7 million more have died.

Steve admitted to having once been largely ignorant to the prevalence of the disease.

"I didn't think about [HIV] at all before. It was a distant thing," he said.

Facing Columbia after Contraction

He described how he contracted the virus, two and a half years ago, when he was working in Boston.

"I was in a vulnerable point ... looking for someone to fill me up," he said of the trust he put in his boyfriend. The two had intercourse without a condom on several occasions, always under the influence of drugs and alcohol.

A few weeks after the relationship ended, Steve came down with a month-long case of severe stomach flu. He did not see the doctor at the time, unaware of the significance of his illness. Doctors estimate that up to 80 percent of all newly HIV-infected individuals will experience symptoms of acute viral infection, beginning shortly after HIV enters the bloodstream, and lasting as long as 10 weeks or more.

Steve said that after his recovery he felt physically well, but describes a "strange spiritual sensation," feeling as if something were inside of him, though he did not know what.

"God, I wish I could get this out of me," he remembered thinking.

Five months after his illness, he was beginning another relationship, and went in to be tested for HIV. He went initially out of routine, though suspecting, if only subconsciously, that something was wrong.

Steve seemed at a loss for words, and even reluctant to describe the experience of testing positive. He turned his head away.

"You hear it ... and I was totally present ... and I didn't know what to do," he said.

"I went into business mode," he remembered, facing forward again. Just about to start at Columbia, he had three weeks to

move to New York.

One of the first people he met at Columbia was Laura Pinsky, director and co-founder of the Gay Health Advocacy Project, the nation's oldest college campus HIV test site. Pinsky counsels much of Columbia's HIV-positive community, assisting them with both psychological and medical needs. She helped Steve to take advantage of a range of support offered by the University Health and Psychological Services.

"It really helped me to thaw out," Steve said. "It saved my life at that point. I don't know what I would have done."

According to Pinsky, "Columbia students can get the best state-of-the-art HIV care from a combination of Columbia Health Service doctors and outside experts. The care is free and confidential. Extensive psychological support is offered."

Students who test positive for HIV, including Steve, are referred to Dr. Michael Giordano, one of the top HIV specialists in the country.

According to Dr. Richard Carlson, director of Columbia Health Services, "It is essential for somebody who is HIV-positive to at least pass through the hands of someone who is a specialist with HIV care. The new medications are great, but you need to work with somebody who is an expert."

Dr. Carlson was referring to the new, powerful combination therapies. Since their introduction in early 1996, a new class of anti-viral medications called "protease inhibitors" have been used in conjunction with older, more established drugs to reduce levels of the HIV virus in the blood often to undetectable levels. Subsequently, AIDS death rates have dropped approximately 70 percent in this country—from a peak of about 48,000 deaths per year in 1994 and in 1995, to 14,338 deaths in 1997.

Staying Strong with New Medication

As a result of his treatment, Steve calls his health "totally perfect—maybe even better than most people."

Pinsky shares Steve's optimism: "For most of the HIV-positive students at Columbia, it is reasonable to expect that the prognosis for their staying alive and healthy for a long time is excellent—perhaps as long as anybody their age," she said.

But treatment comes at no small cost. Therapies can run a tab of up to \$12,000 per year for medications alone. Total treatment costs soar to as much as \$40,000 per year.

Steve is lucky—every aspect of his coverage, from viral load tests to counseling, is either covered by his Columbia health insurance or written off by Dr. Giordano. His medications are provided to him for free by the New York State AIDS Drug Assistance Program, which provides financial assistance for the medications of almost 14,000 HIV-pos-

itive, lower income state residents.

Steve's medications keep him on a strict regimen. Missing even one dose has the potential to render the drugs as useless. He takes three different drugs in different combinations at 8 a.m., 4 p.m., 8 p.m. and midnight—a total of 13 pills a day, or 4745 a year.

"Most of the time, it's not a burden," he said, and has missed only one dose to date.

Like so many others, Steve deals with the resulting side effects of his medication. One of the initial protease inhibitors he was prescribed gave him seven months of often severe diarrhea. He eventually switched medications, which now leave him chronically dehydrated, and sometimes with severe heartburn.

Steve believes fat from his arms and legs has redistributed around his abdomen, though it is not noticeable if he exercises regularly. His experience with this common symptom is mild compared to some who experience fat deposits on the back of the neck so large they are referred to as "buffalo humps." Many others cannot take the new drugs at all as a result of other intolerable side effects, and are left with few treatment options.

Overcoming the Experience

Steve is working hard to overcome his fears of openly acknowledging his HIV positive status.

"I think I'm at a point where I'm not so afraid of being identified with the disease. I've become more comfortable with it. So it's easier for me to admit it without feeling hateful of myself," he said.

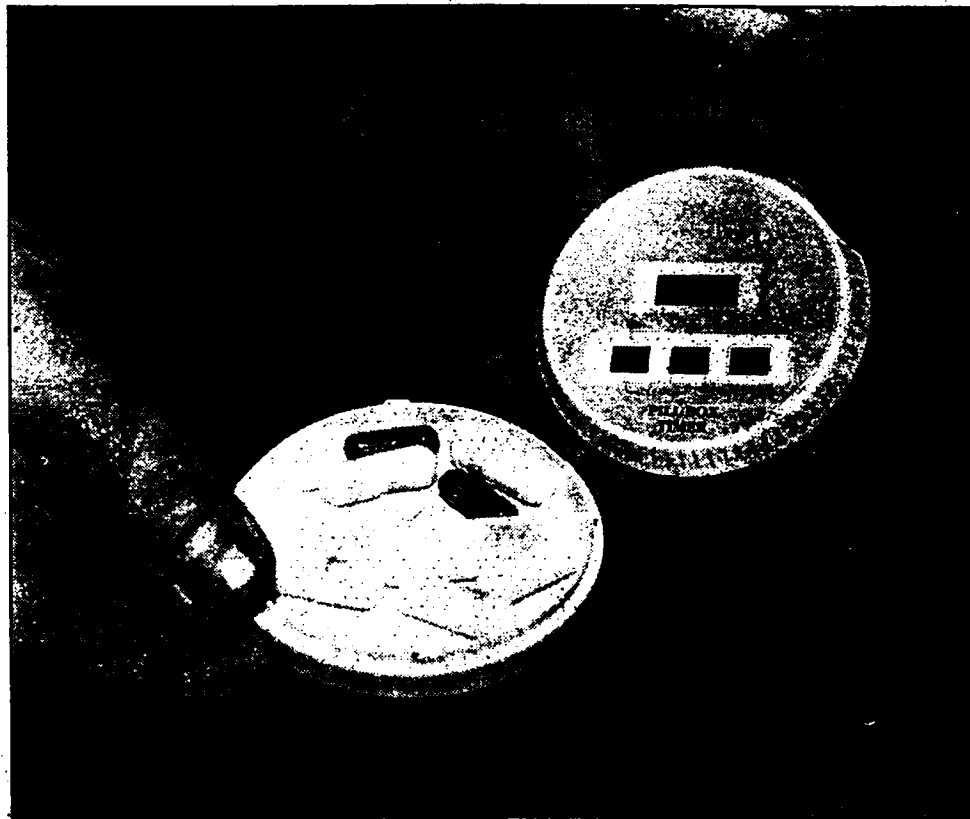
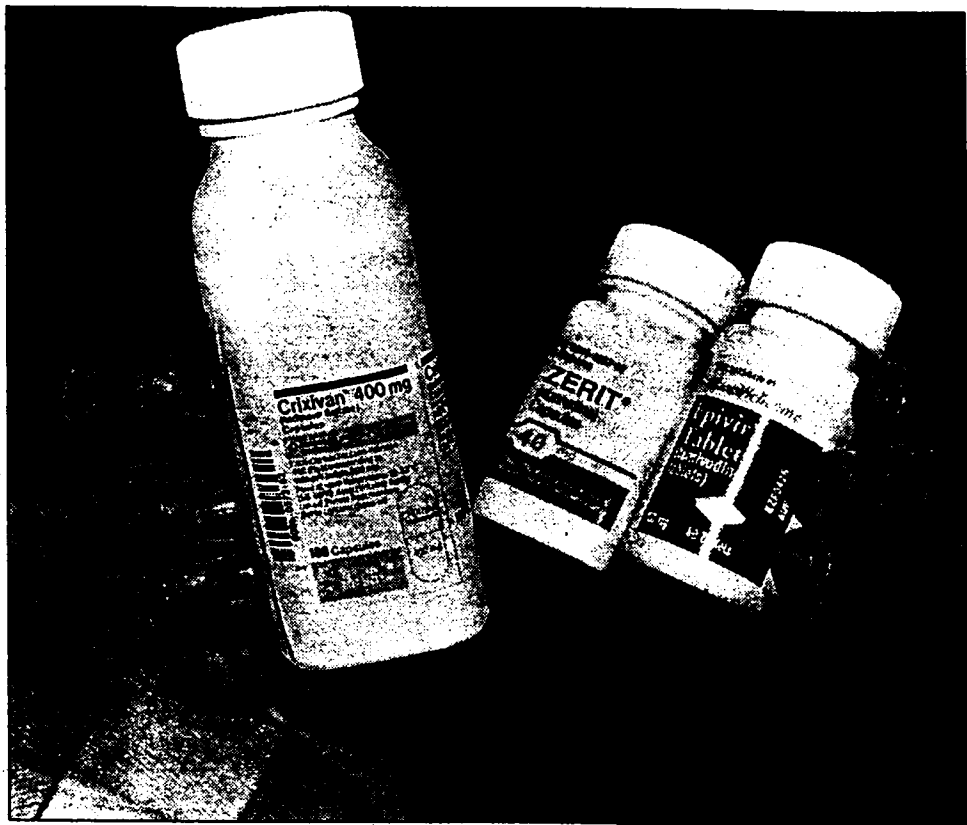
No doubt, HIV has been a life-changing experience for him. In some ways, he seems a stronger person because of it. Rather than being a detriment to his work at Columbia, the disease has only served to propel him.

"Late at night, I think about dying, getting the things done I want to get done. I want to believe that the drugs will help me maintain a normal life. I feel like I've pushed myself so hard ... harder than I would otherwise.

"The lessons I've learned from getting it far outweigh the negative. It's opened up a lot of emotional areas, changed me in a really wonderful way. It's given me a sense of empowerment of how I want to use my time," he said.

Steve's eyes lit up again as he talks of his dreams for the future: to be successful with his work as an artist, and be seen by the largest possible audience; in other words, to make his mark. He hugged his knees to his chest and tells of his dreams of finding someone to share his life with.

He smiled. "Testing positive makes you realize the span of a life," he said. "You're not here that long, so you gotta do what you gotta do."



CONTRIBUTING PHOTOGRAPHER—BEN RYAN

'Steve' has to take 13 pills at four different times every day to control his HIV. "Most of the time, it's not a burden," he said, and he has missed only one dose to date.