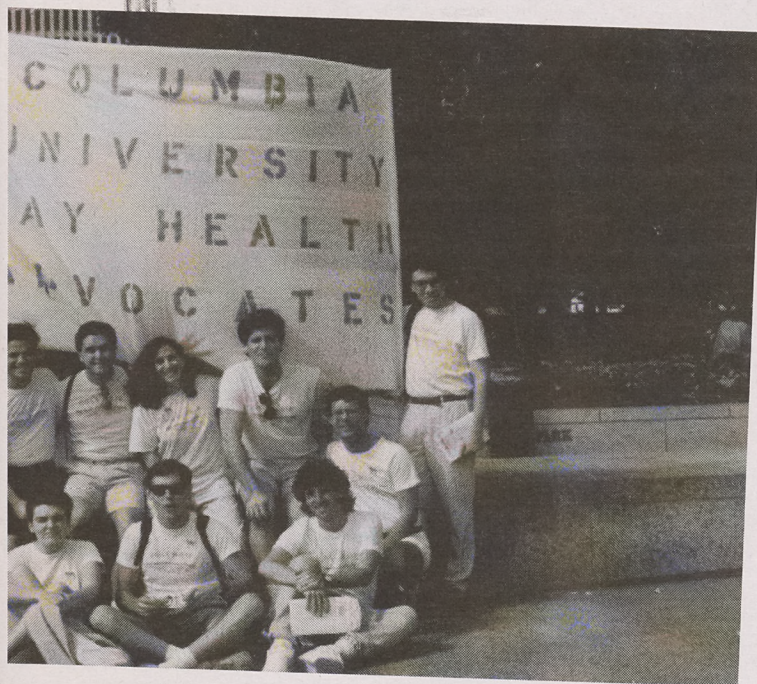


U Like A Good Fight?

FIGHT ON

THE STORY OF AIDS AT COLUMBIA

BY WILL HUGHES



Note: The author is a current advocate for the Gay Health Advocacy Project. The names and identifying information of certain individuals have been changed to protect the anonymity of those interviewed.

I woke up with a fever, and a headache behind my eyes, and within three days I had lost 10 pounds, and I was sweating all the time and itchy all the time. And I knew what was going on. I had read enough WebMD pages to know that those were the signs."

Andrew is a gay male graduate student at Columbia. About a year ago, he moved to New York from Los Angeles to pursue a master's degree. In Los Angeles, he had started having anonymous sex, sometimes protected and sometimes not, and using crystal meth, a drug that goes hand in hand with sex in certain segments of the gay community. Throughout this, HIV was always on his mind. In West Hollywood, the gay enclave of Los Angeles, billboards about getting tested are ubiquitous, and when having sex, conversations beforehand about one's HIV status are the norm.

"It was always on my mind. Just by being homosexual, I have HIV. It was something I always worried about ... And it was just this major cause of anxiety." When Andrew moved to New York, he started having more and more anonymous sex, and using more crystal meth. During the break between fall and spring semester of the last academic year, he went on a two-week binge, culminating in an incident that left him determined to change his habits.

Two weeks after that, he woke up with a fever and realized he should get tested.

In 1981, what eventually became known as AIDS was first documented in Los Angeles, when five gay men died of a rare form of pneumonia. By 1985, AIDS had spread to every major city in the country, killing over 15,000 people in the United States and 5,000 more internationally. In those four years and those that followed, the response to the disease was invariably affected by the demographics of its victims. AIDS most commonly infected gay men, as well as intravenous drug users and racial minorities: groups that, in the conservative climate of the 1980s, were not viewed favorably. A government defined by budget cuts under President Ronald Reagan gave very little money to AIDS research, and high-level administrators covered up the inadequacies in funding. Furthermore, mainstream scientific researchers were wary to invest or associate themselves too closely with a "gay disease." Until mid-1983, the Centers for Disease Control and Prevention referred to AIDS as GRID, or Gay Related Immune Deficiency, which cemented its reputation in the public mind.

Based on epidemiology, scientists were able to hypothesize correctly that safe sex practices would greatly reduce the spread of HIV, and that casual contact (kissing, hugging, shaking hands, etc.) bore no risk of transmission. Still, the fear of AIDS remained very strong, and played into long-held stereotypes of gay men. Prominent religious and political figures called AIDS a punishment from God for the deviancy of homosexuals. AIDS was seen widely as a moral

problem rather than a medical one, creating a strong and enduring stigma surrounding the disease that led to numerous problems in fighting it.

While the story of AIDS was playing out on the national stage, it was also unfolding on a more local level. Columbia, located in the epicenter of the epidemic, had its fair share of cases in the early 1980s among students and staff. In 1983, an employee sued the University for not fulfilling his benefit package by not covering hospital bills incurred due to AIDS. A student, heavily involved in student council and service organizations on campus, graduated and then died a month afterward. Professors would develop

pneumonia, outing them as both having AIDS and being gay, and would get blackballed from any tenured position.

In late 1985, Columbia formed a committee to come up with a policy on AIDS for the University. Leading the committee was Joseph Mullinix, executive vice-president and chief administration officer, a senior administrator whose priorities lay in cutting costs and protecting the University from legal action. Various health admin-

istrators, professors, and public health professionals populated the lion's share of the committee.

Laura Pinsky represented the counseling service, which at the time was located in John Jay Hall and was split into two departments, one for graduate students and one for undergrads. A 1969 graduate of Barnard, Pinsky had been involved in the 1968 political action on campus. When she was hired in 1984, she was assigned to work with students who had chronic illnesses and diseases with a psychiatric


component. As her caseload increased, she started working more and more with students who had concerns about AIDS, and because of this involvement was chosen for the committee.

Among the student representatives was Paul Douglas. Openly gay, tall, and, by all accounts, very attractive, Douglas was getting his PhD in computer science. His role on the committee was to represent the interests of both the gay community and students who tested HIV positive.

After a few meetings of the committee, two things became clear: the most powerful representatives of the University were concerned predominantly with insulating the school from liability, and that there was a pressing need for information and counseling about HIV/AIDS on campus. Organizing a group of friends and identified supporters, Pinsky and Douglas created the Gay Health Advocacy Project, or GHAP, with the mission of providing information to the student body at large about AIDS.

The first meeting was held on October 15, 1985. The notes from that meeting read, "We drink champagne from specimen cups to celebrate the start of the program—a feeling of energy, attention, and good will in the room with some tension—we start with a lot of business—setting our contract and boundaries—smoking debate—the non-smokers win." Every advocate was given a huge packet of materials on basic immunology, current CDC reports, and articles not yet published in scientific journals. The first step of the program was to become as knowledgeable as possible about HIV. In a time when treatments were few and far between, it became common for patients to know more than their doctors did. There was nothing else for people to do, so the impulse to fight turned into the impulse to know everything that was out there.

GHAP turned its attention to what they would do after research. The advocates would be peer counselors, talking to people in a sex-positive, gay-positive way (both particularly noteworthy for the time) about how to reduce their risk and, if they were positive, preparing them for the future and offering support



Columbia Gay Health Advocates are fighting the threat of AIDS on campus.

You can help defeat both AIDS and unnecessary fears by becoming informed.

Our services are available to men and women, gay or straight. They include public information, individual counseling, and discussion groups on such topics as:

- Coping with AIDS anxiety
- Avoiding unsafe sexual activities
- AIDS and pregnancy
- Whether and how to take the antibody test

We also provide information about other sexually transmitted diseases and the Hepatitis B vaccine.

Want more information? Call 280-2878

Call 280-2878 weekdays between 9 am and 5 pm. This is the number of the receptionist at the Mental Health Division of the Health Services. Ask for the GHA Program. A health advocate will speak to you immediately if available. If no advocate is available when you call, you can either leave a telephone number and instructions for us to call you back (e.g., hours, use discretion), or you can ask for a time when you should call us back.

An evening to feed your mind and your body...

AIDS 101 Pizza Blast

Whether you are gay or straight, female or male, you need to know the facts about AIDS. Come and listen to AIDS 101 while enjoying

FREE PIZZA AND DRINKS!

Tuesday, July 14th at 7:30 p.m. Dodge Room, Earl Hall Columbia University

Sponsored by the Columbia Gay Health Advocacy Project. For more information, call 280-2878.

groups. Advocates would also visit dorms and give basic AIDS 101 talks called "floor raps." Pinsky and Douglas were soon asked to perform regular speaking engagements, for organizations on campus as well as other groups within the city. GHAP advocates were also involved in a number of activist groups, including ACT UP (the AIDS Coalition To Unleash Power), and took part in some of the most visible demonstrations of the group.

In a time when gay men were dying constantly and unpredictably, GHAP became a way to fight back against both the disease and the moralism that dominated the conversation. Nash Professor of Law Kendall Thomas, who sat on the AIDS committee, says, "There were people both within the gay community and outside of it who were more than willing to draw a connection between AIDS and what they saw as the excesses of the late 1960s and 1970s and the loss of a world (which never really existed) in which men were men and women were women, and homosexuals stayed in the shadows. There was no public homosexual culture in this country until the emergence of the so-called sexual revolution. So it led to some profound questioning, and frankly more than a few of us wondered, 'Maybe they are right. Maybe there is a connection between this terrible disease which is taking the lives of all of these really beautiful young men and the sexual ethics that emerged during the 1970s.'"

GHAP worked against this line of thought. Speaking in terms of public health and medicine, as opposed to sin and deviancy, GHAP encouraged its members to rally together and to seek knowledge about the disease rather than ignore it or wait to die. This accomplished something stronger, and

something mirrored nationally: the forging of a gay community that took care of its own.

The same afternoon he woke up with a fever, Andrew came in and met with a GHAP advocate at Columbia's Health Services. They talked through the mechanics of the test and assessed his risk, and for the first time, Andrew told someone what he had been doing. That experience of talking for the first time about his dark secret made him feel better. He had his blood drawn and went home, still anxious.

Andrew came back the next afternoon and met with Daniel Chiarilli, the coordinator of GHAP. They talked, just as in the initial interview, about what he had been doing and how he was feeling. Similar to the first meeting, he felt an immediate closeness and trust with Chiarilli. Andrew then met with a doctor in Health Services, who performed a panel of STD tests. After Andrew had returned home, he received a call, telling him to come back to the office. The doctor told him he was HIV positive.

"I think my first reaction was almost to laugh, like what did you think was going to happen. You spend all this time stressing out over this thing, getting this thing, you wouldn't have to stress out if you weren't behaving the way you're behaving, engaging in the activities you are engaging in. But I didn't laugh about it for terribly long."

Being positive in 1986, when the HIV-antibody test was first used, was a grim reality. No drugs had shown any effectiveness against the disease, and the prognosis was invariably death. To test positive for HIV meant knowing that you would

almost certainly develop, at some unknown point in the future, a fatal illness. The analogy most commonly used is a bus: Having HIV was having a bus coming down the road. You didn't know when it would hit you, only that it was coming.

Researchers across the street at St. Luke's Hospital were looking into the connection between certain gastrointestinal issues and HIV, and the main scientist, Dr. Donald Kotler, needed a group of HIV-negative controls for the study. He approached GHAP, and because this was before the FDA officially approved HIV antibody testing, the majority of its members decided to get tested. It represented the first opportunity for the members of the group to know whether or not they had the disease they had spent so much time learning about. When the results came in, almost everyone had tested negative, including Douglas, who had long been convinced he would test positive.

In a twist of fate, the lab called the next day to

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inform Pinsky there had been a mistake. The blood samples from Douglas and another advocate had been swapped accidentally. Douglas was positive. Pinsky went over to his apartment, and told him what had happened. His reaction, she describes, was quiet. Shortly after telling him, he uncharacteristically asked her to leave. It was the first time she had to give a true positive result.

When he heard the news, Andrew thought he could say, "Thank you so much," and then go find someone on Craigslist for drugs and sex. He could fuck him for a couple of months, eventually killing himself with drugs. For years, he had been anxious about HIV, and always told himself that if he ever got it, he would commit suicide. There would be no telling anybody, no shame, and no giving it to anyone else. He remembers, "In that moment when the doctor told me, I really felt, I think it came up in my head, 'Oh, you have a plan for this,' and almost immediately that went away. And it never since has really been a consideration; it hasn't been a consideration at all. It really made me want to live."

*Laura,
Thanks very much for
the two copies of "The Emotional
Aids Just Book."*

*We've added the books
to our reference collection.*

*Thanks again for your
important contributions*

Kendall

That day, he spoke to Daniel again and, the next day, saw Dr. Steven Radowitz, one of the preeminent HIV doctors in the city, and began taking medication. Andrew also had an appointment that day with Laura Pinsky, who still works as a social worker in Counseling and Psychological Services. They immediately began to work together in therapy to process what had happened, work that would continue for a number of months.

The day he found out, Andrew told one person. Tom was a man he had met a few weeks before, right after the end of the binge, and they had gone on a few dates. They hadn't had sex, but they had been physical together enough so that Andrew felt Tom should know. It was also clear that they were romantically interested in each other, and the fact that they had plans for that night did not leave Andrew with much time to mull things over.

In the moment he told Tom, he was sure that it would be the end of the relationship. Instead, he found the opposite reaction. Tom didn't express concern about the ramifications for his own health; he only asked how Andrew was processing everything. Andrew describes "this beautiful kindness that was shocking to me, that same kindness that I was getting out of Daniel and Laura." While there were many uncertainties moving forward, his first experience telling someone had gone unexpectedly well.

Due to the lack of consolidated information on AIDS, by 1986, GHAP advocates were among the most knowledgeable people on campus about the disease. Meetings of the AIDS committee were contentious, although never adversarial, and influenced frequently by emotions and political concerns rather than science and public health. A senior professor who sat on the committee expressed discomfort with the possibility of his son living with a student with HIV, despite knowing that impossibility of casual contact transmission was impossible. Pinsky and Douglas prepared a report for the committee based on the research they had been doing for GHAP, that outlined basic transmission information as well as what to do if you were positive. Almost all the literature that was coming out at the time assumed that its reader had tested negative, meaning the narrator was ignoring those who needed the information most. Furthermore, Douglas's own HIV status and his presence on the committee was a constant reminder that AIDS was not a disease that happened only to other people, but instead permeated the walls of the ivory tower.

This report was eventually published and distributed to all undergraduates. The booklet was undeniably informative, and very soon after its distribution, the committee was inundated with requests from various other Columbia offices for copies. Repackaged as being authored by "The Columbia University AIDS Committee," thousands of copies were distributed free of charge. In an internal letter to the president of the University, Michael Sovern, Mullinix wrote, "While we are not eager to have the University closely identified with a

controversial issue such as AIDS, we believe that a substantial public service can be effected."

Shortly after the success of the Columbia booklet, Pocket Books approached Pinsky and Douglas about a commercial printing. After another revision and update, the report of the committee was published in 1987 as "The Essential AIDS Fact Book." It was very successful, going into four printings, and sold in bookstores and supermarkets nationwide. Organizations ranging from other universities to the United States Marine Corps placed bulk orders for the book, which ended up selling hundreds of thousands of copies and was translated into four languages.

GHAP continued its scientific work in other arenas: An advocate, Gerard Ilaria, wrote a paper published in *The Lancet*, one of the world's leading medical journals, on the risk of transmission from pre-ejaculatory fluid. Pinsky and Douglas organized annual conferences titled "AIDS: Improving the Odds" from 1987 to 1989. Bringing together scientific experts, community organizers, gay leaders, and drug researchers, these conferences were packed to the brim.

The first conference was held in a large conference room in the Columbia Law School. Pinsky and Douglas arrived an hour early to set up and found guards in the lobby frantically attempting to contain a semi-riot of people vying to gain entrance to the first-come-first-serve event. Because of the desperation and seriousness of the topic, the conference was raucous, with people shouting over each other and heckling the speakers. The conference was also attended by members of the AIDS denialist movement, which

argued that AIDS was not real and that AZT (then the drug of choice against it) was a poison designed to kill homosexuals. GHAP ended up holding "AIDS: Improving the Odds" again in 1989, in Miller Theatre. Both conferences, logistical issues aside, provided a great amount of information and the transcripts were widely circulated.

GHAP's place within Columbia Health has changed. In its early years, GHAP received funding from Health Services but was organized under Earl Hall. Over time, the coordinators that ran the day-to-day operations of the group turned the long-standing support from key individuals into a full integration with Health Services. Today, GHAP has an office and dedicated rooms within Health Services for counseling, and strong relationships with the primary care providers. Just as it has been from the beginning, volunteers from various schools within the University staff the organization entirely. It administers some 1,300 tests annually, and

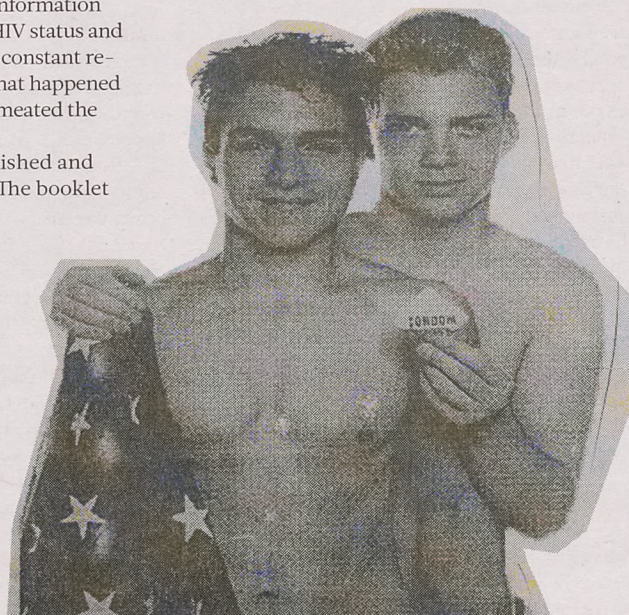
for those few like Andrew that test positive (about three to six a year), there is strong follow-up care, both medical and psychological. Pinsky remains the director of GHAP, and for positive students, provides practical and psychological support.

Gone are the mandatory floor sessions during orientation, as well as the two-week waiting period for results. Furthermore, the name "Gay Health Advocacy Project" strikes many people as out of place, either because the service is so widely used by straight students or because "gay" is not as encompassing as "queer" or "LGBTQ." The group has kept the name, first to honor those who founded it, who were almost exclusively gay, and second, because although AIDS is not a gay disease, almost all of the positive students on campus remain gay men.

Andrew is doing well. He takes four pills once a day at 6 o'clock. Every day his phone alarm goes off to remind him. For a while, he thought about it constantly, but now, it is not really on his mind aside from every day at 6 o'clock. He says, "In terms of my emotional and mental health, I have said before, and I think it might be a little bit hyperbolic, but it also might be true, HIV kind of saved my life. Because if I hadn't gotten it, how soon would I have gone back to that, how soon would I have found myself on another binge, this time three weeks, and the next time two months, and suddenly I'm scratching my skin off and my teeth are falling out. How soon would that have happened? I don't know."

Andrew's story is not the case across the board. There are clinics all over the city, but due to time and money constraints, they are often unable to provide the level of personalized follow up that GHAP can. Moreover, the positive rate at Columbia is much lower than it is in the city as a whole, so the support for positive students is proportionally greater. But most of all, GHAP has 27 years working with preeminent AIDS doctors and researchers,

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Columbia AIDS Alert

Spring 1988 Issue of the newsletter of the Columbia Gay Health Advocacy Project

Students at Risk for AIDS Offered Expert Treatment Through the Columbia University Health Service

If there is any chance that you are infected with HIV, the virus that can cause AIDS, you should be aware that expert treatment is available here on campus through the University Health Service.

A recent study has shown that the pneumonia that has been responsible for 60% of fatalities from AIDS is now generally preventable. If you might be infected with HIV (the virus that can cause AIDS), you should be evaluated and followed by a health care provider expert in AIDS so that, if necessary, you can begin preventive therapy against this pneumonia and other aspects of HIV illness at the earliest time possible.

Confidential, expert medical care and support is now available through a new experimental program of the University Health Service at no cost beyond the regular fee. Assisted

by the Columbia Gay Health Advocacy Project, the Health Service provides a comprehensive program of care and support for HIV-infected students, including:

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- Potentially life-saving treatment available on campus
- Project documents harassment and discrimination
- AIDS Committee Report released
- AIDS Memorial Quilt coming to Columbia
- Condom Awareness Week at Columbia
- 800 attend conference on early treatment for AIDS

• Regular visits with a health care provider expert in the care of HIV-infected people

• Periodic laboratory evaluation of the immune system at no extra payment, including lymphocyte subset studies (T4-cell count, T4/T8 ratio)

(Continued on page 2)

AIDS COMMITTEE RELEASES REPORT

What follows are excerpts from the Report of the Columbia University ad hoc Committee on AIDS, released this spring after nearly two years of research and deliberation:

...Present evidence has documented HIV infection only through sexual intercourse, the sharing of intravenous drug

paraphernalia contaminated with fresh blood, the receipt of contaminated blood or blood products, or perinatally from infected mothers to their fetuses. All current medical evidence indicates that casual contact, such as working together, living together in dor-

(Continued on page 3)

"HEY AIDS FAGGOT!"

Project Documents Homophobic and AIDS-Related Harassment and Discrimination

On March 1st, thirty men and women attended a discussion marking the start of a new effort by the Columbia Gay Health Advocacy Project (CGHAP) to document homophobic and AIDS-related harassment and discrimination on the Columbia campus.

Margaret McCarthy, a longtime Gay Health Advocate and an intern at the New York City Commission on Human Rights, described the new program:

"Harassment and discrimination have always been a fact of life at Columbia for gay men and lesbians, but AIDS has made things even worse. We want to document this to bring it to the community's attention and to show the University that this is not going to be swept under the carpet. People who have been harassed or discriminated against because they are perceived to be gay or because someone believes that they are at risk for AIDS should contact CGHAP's Documentation Project.

Examples of harassment are: name-calling, offensive graffiti, "cold-shouldering," vandalism, sexual harassment, and threatened or actual physical violence. "We are particularly interested in those incidents in which harassers try to

(Continued on page 4)

giving it both the experience and the connections to provide the best care.

Andrew and his boyfriend are soon to celebrate eight months together. As it became clear that things were moving in a serious direction, they decided to keep seeing each other, and take it slow. After two months, they had a serious talk: "I feel like I'm growing attached to you. I'm feeling loving feelings for you and, on one hand, I don't want to go too far down that alley if one day you're going to say, you know what, I can't be with someone who's positive, sorry. On the other hand, I don't really care if you break my heart, because I'm enjoying this," Andrew said. Tom responded, "You know, there was definitely a time in there where I thought, oh gosh, I'm definitely going to break his heart because this is too big a thing, this is too big a hurdle." But then they decided together not to care for just now.

That is how they have been since. HIV does not govern their relationship. They are still physical, in a safe way, and because of medicines and other precautions, Tom's risk is miniscule. They both know that at 6, Andrew has to take his meds.

"He is just so kind and supportive, and I never, I don't think I understood before dating him how important a quality kindness is and how it really is all that matters ... I just think what is the alternate universe to this journey, what is the other journey, and I just am so lucky that this is the one, that this was the experience, because the other one, I think, is very dark. I feel lucky."

Paul Douglas died in 1995 of complications from AIDS. He had been the first advocate to test positive for HIV in 1985 and continued to work with the group for the last 10 years of his life. His memorial service downtown filled St. Mark's Church. There was not one empty seat. When he died, he was on the waiting list to start a drug trial for protease inhibitors, a key component of the cocktail of anti-retroviral drugs that allows people like Andrew to live with few of the medical consequences of being positive.

"The influence he had had and Laura had had broadly, not only at Columbia but around the city and around the country, was really astounding.

Even when he knew that it was probably inevitable that he would die, he never stopped. And that was the spirit that eventually emerged from all this, which I think is really quite extraordinary. That is the Columbia that I know and love," says Peter Awn, dean of the School of General Studies.

In a session given in 1988, Douglas counseled a young gay couple that was at significant risk for AIDS. Both of the men had had many instances of unprotected sex, as they learned of the necessity of using condoms in 1987, six years into the epidemic. They were almost certainly going to test positive, but did not want the test performed, because they believed that knowing their status would inevitably ruin their summer together.

Paul wrote in the report of the session, in the form of a letter to Laura, "[They] are a young couple, very much in love ... they seem devoted to each other and plan to spend the rest of their lives together." He ends the summary with a quote from *Waiting for Godot*: "The tears of the world are a constant thing ... we give birth astride of a grave. The light gleams for an instant and then is extinguished forever." ●