

NARRATIVES OF NORTH CAROLINA EPIDEMIOLOGY:  
HIV GOES BACK TO COLLEGE

by  
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A thesis submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Arts in the School of Journalism and Mass Communication (Medical Journalism).

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ABSTRACT  
ANTON ZUIKER: Narratives of North Carolina Epidemiology:  
HIV Goes Back to College  
(Under the direction of Thomas Linden, M.D.)

In 2003, state and university researchers discovered a rise in incidence of HIV among college students in North Carolina over the years 2000-2003. This increase included 84 students from 37 colleges and universities across the state; the majority of the students were African-American males and contracted HIV through sex with other men. A new HIV screening program that tests for acute HIV infection helped to identify the college cases, and the state's partner notification and counseling program was also helpful in tracking the sexual networks that connected the students and their campuses. In an introductory chapter, I review AIDS journalism and narrative writing and provide background to the N.C. outbreak. In the main chapter, I present a narrative-style non-fiction magazine article that explores the work of researchers, epidemiologists and public health officials in response to the N.C. college HIV increase.

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## CONTENTS

Chapter	Page
1. AIDS JOURNALISM .....	1
2. “BACK TO SCHOOL” .....	22
3. SOURCES .....	58

## LIST OF ABBREVIATIONS

AIDS	acquired immune deficiency syndrome
CDC	Centers for Disease Control and Prevention
ELISA	enzyme-linked immunoadsorbent assay
GLBT	gay, lesbian, bisexual and transgender
HBCU	historically black colleges and universities
HIV	human immunodeficiency virus
JAMA	Journal of the American Medical Association
MSM	men who have sex with men
NC	North Carolina
PCR	polymerase chain reaction
RNA	ribonucleic acid
STD	sexually transmitted disease
STI	sexually transmitted infection
STARHS	serologic testing algorithm for recent HIV seroconversion
STAT	Screening and Tracing Active Transmission
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNC-CH	University of North Carolina at Chapel Hill

**F**or most villagers on Paama Island in the Republic of Vanuatu, Saturdays are garden days. Families hike early in the morning to their gardens on the steep hills to tend their yams and watermelons and kava plants. The village of Liro and its seaside school are quiet and still, with South Pacific breezes to cool a Peace Corps Volunteer swinging in a hammock. The school week is finished, and this is a good time to read. Novels, *Newsweek* or months-old *New Yorker* issues can occupy hours before tests must be graded and the next week's lessons planned.

It is 1998, and amid the cacophony of a sex scandal and impeachment intrigues, the magazines mention AIDS, an epidemic raging around the world. South Africa is often in the spotlight. There, more than 20 percent of the population is estimated to be dying of AIDS. But in this corner of the Pacific, so many thousands of miles away from the dying South Africans, Vanuatu has yet to see a single case of HIV or AIDS. In a sea of global AIDS, this nation of islands is literally unto itself.

But there are other illnesses.

One day, my wife rushes home from a visit to a village down the coast. She's been out on a boat in a rainstorm, and she's shivering. The rain and her shivers are coincidental – malaria is beginning to wrack her body. She's already fought through dengue fever, another mosquito-borne infectious disease. In the next few weeks, she'll recover from malaria with the help of chloroquine, but she'll get so sick from that drug that she'll need to take anti-nausea medication – and that will lead to acute dystonia, in which her jaw muscles will

spasm and then lock tight in a grotesque mask. The Peace Corps nurse will take good care of her, and she'll be back at work in the island's health clinic.

Elsewhere on the island, men, women and children suffer from malaria, dengue, filiarisis, giardia and tetanus. Others live with scars of polio and Hansen's disease. (My hammock reading also included *The Control of Communicable Diseases Manual* and *Where There Is No Doctor*.)

A few years before my Peace Corps service, bookstore shelves started bulging with new books about infectious diseases – *The Coming Plague*, *The Hot Zone* and others. In the years since, newspaper headlines have offered a steady diet of infectious disease news, with stories about influenza and Ebola, mad cow disease and anthrax, smallpox and SARS, hepatitis A and cholera. These headlines long ago shattered the presumption made by Surgeon General William Stewart in 1967 that it was time “to close the book on infectious diseases.”<sup>1</sup> At that time, Stewart and other public health officials could point to the successes of antibiotics and vaccinations. Indeed, smallpox would soon be eradicated from the planet, so why not all the other infectious illnesses?

But just as smallpox was being wiped out, HIV/AIDS began spreading from the jungles of central Africa. It hit the U.S. in 1981. Within a few years, HIV/AIDS was a big story.

Human immunodeficiency virus (HIV) causes acquired immune deficiency syndrome (AIDS). HIV is a sexually transmitted infection, but it also has other important modes of transmission, including intravenous drug use and blood products. HIV is a complex retrovirus, and there is no known way to completely eradicate the virus from the human

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<sup>1</sup> William Stewart, “A Mandate for State Action,” presented at the Association of State and Territorial Health Officers, Washington, D.C., December 4, 1967.



body. HIV leads to AIDS, which in the end is always deadly, although there are a dozen powerful drugs that, when combined, can keep the virus at bay for many years.

HIV/AIDS continues to be a major global health problem. UNAIDS, the consortium of United Nations agencies that have HIV/AIDS programs, estimates that 40 million people are currently living – and dying – with the virus. This year 3 million individuals will die of AIDS, and another 5 million will contract HIV.<sup>2</sup> That means HIV/AIDS is still a *growing* major global health problem. The nations of Sub-Saharan Africa are hardest hit, but nations in the Caribbean and Latin America, Asia and the former Soviet Union are also staggering under HIV/AIDS epidemics.

“This will be a 200-year epidemic, and your grandchildren will still be dealing with this,” says Dr. Myron Cohen, an AIDS expert and director of the Center for Infectious Diseases at the UNC School of Medicine. There is as yet no immunization for HIV. No cure for AIDS. Currently, more people get HIV each year than die from the disease. The epidemic continues to grow.

And yet 20 years of headlines and tragic stories seemed to have lulled Americans into a false sense that HIV/AIDS is under control. It’s not uncommon to hear teachers and preachers and community leaders say, “But everyone knows about AIDS.” Unfortunately, they don’t.

The Centers for Disease Control and Prevention (CDC) estimates that nearly 40,000 Americans contract HIV each year. But most of those 40,000 newly diagnosed HIV-positive individuals will have access to anti-retroviral therapies, cocktails of powerful drugs that can

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<sup>2</sup> UNAIDS/WHO, *AIDS Epidemic Update 2003*, (Geneva: Joint United Nations Programme on HIV/AIDS, 2003), 7, available online at [http://www.unaids.org/wad/2003/Epiupdate2003\\_en/EpiUpdate2003\\_en.pdf](http://www.unaids.org/wad/2003/Epiupdate2003_en/EpiUpdate2003_en.pdf) (accessed 7 April 2004).

control the amount of HIV in the body for many years. In 1985, says Cohen, 10 percent of the patients admitted to the UNC Hospitals were AIDS patients, who were seen in the infectious diseases ward. “Now it’s rare for that ward to have one patient,” he says. Perhaps this is what has led many Americans to think that HIV is no longer a death sentence.

Of course, that’s not the full story.

Wall Street Journal reporter Mark Schoofs won a Pulitzer Prize for his reporting about AIDS in Africa. He spoke to the Association of Health Care Journalists in March 2003, urging them to refocus their reporting on HIV/AIDS. Here’s what he had to say:

[W]e are certainly under-reacting to the danger of infectious disease. . . . But we do know that malaria kills about as many people as died in the twin towers, a little less than 3,000. But malaria takes this toll every day of the year. Tuberculosis kills almost twice that number, 5,500 people, many of them coughing up not grey ash, but dark, infected blood. And, again, TB kills this huge number every day. As for AIDS it is estimated to be killing about 8,000 people every day. The cumulative toll of just these three diseases exceeds 15,000 people a day. That’s five World Trade Center attacks, ten towers collapsing, every day.

This is not merely tragic. This is scandalous, because malaria and TB are easily and cheaply cured, and AIDS can be held at bay— put into a kind of remission, if you will— for many years. So these deaths by infectious disease are not “natural.” They are the result of human action—and inaction. These deaths are manmade.

That’s the moral reason why we should keep writing about AIDS and other infectious diseases: a manmade catastrophe of this scale should be covered every day. It is a big story.

But there’s another reason why we should cover AIDS and other infectious epidemics—and this reason will probably be more effective than moral arguments in swaying our cynical, hard-bitten, budget-conscious editors: AIDS isn’t just a big story, it’s a great story.<sup>3</sup>

It’s also a North Carolina story. In a conversation this past summer, Cohen said to me, “Call Peter Leone. He’s about to release an important study.” In North Carolina, Leone told me, HIV infections are on the rise in a surprising population – college students.

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<sup>3</sup> Mark Schoofs, “Follow the Virus: Reporting on AIDS,” (presentation at the annual meeting of the Association of Health Care Journalists, San Francisco, California, 15-18 May 2003), available online at [http://www.ahcj.umn.edu/files/03\\_schoof\\_speech.pdf](http://www.ahcj.umn.edu/files/03_schoof_speech.pdf) (accessed 7 April 2004).

## **HIV in North Carolina**

Julie Gerberding, the director of the CDC, wrote in a December 1, 2003 (World AIDS Day) *Washington Post* Op/Ed piece that “the number of people diagnosed with HIV in 29 states increased by 5.1 percent overall between 1999 and 2002.”<sup>4</sup>

North Carolina is one of those 29 states. According to the state HIV/STD Prevention and Care Branch, the number of new cases of HIV infection in North Carolina has risen in the past two years, with an increase of five percent from 2001 to 2002 following a 10 percent increase from 2000 to 2001.<sup>5</sup> That means in 2002 there were about 1700 individuals who learned that they were HIV positive. Sixty-nine percent of those individuals were African-American men and women, an indication that in North Carolina HIV disproportionately affects the African-American community; African Americans in North Carolina have rates of sexually transmitted infections (including HIV) eleven times higher than white non-Hispanics.<sup>6</sup>

From the beginning of the AIDS epidemic in the United States through 2002, a total of 23,770 individuals in North Carolina were reported to health officials as being HIV-positive, and the state health department estimates that at least 21,000 individuals in North Carolina are HIV-positive.<sup>7</sup> What’s more, one-third to one-quarter of them don’t know that they are infected with HIV, say officials from CDC and the state health department.

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<sup>4</sup> Julie Gerberding, “Apathy and the AIDS Epidemic,” *The Washington Post* (1 December 2003): A23.

<sup>5</sup> NC, *AIDS Case Report for 2002, North Carolina* (Raleigh: January 2003), 1-2, available online at <http://www.epi.state.nc.us/epi/hiv/surveillance.html> (accessed 7 April 2004).

<sup>6</sup> NC, *Health Disparities and Trends in HIV/STD/AIDS* (Raleigh, September 2002), p 2, available online at <http://www.epi.state.nc.us/epi/hiv/pdf/HealthDisparities.pdf> (accessed 7 April 2004).

<sup>7</sup> NC, *AIDS Case Report for 2002, North Carolina*, p 2.

“Some 40,000 Americans this year acquired an infection that is 100 percent preventable,” Gerberding wrote. “Unfortunately, less than half of all U.S. adults have ever been tested. CDC estimates that the majority of new HIV infections in this country are transmitted by people who remain unaware of their status.”<sup>8</sup> These increases included a 17 percent rise in HIV among gay and bisexual men. That is hitting home in North Carolina, where 30 percent of newly diagnosed HIV-positive men report having had sex with other men.<sup>9</sup>

And now researchers have recognized that the number of cases of HIV on the campuses of North Carolina’s colleges and universities seems to be increasing: across the state, more than 80 men – almost all African-American – have contracted HIV in the last four years.<sup>10</sup> “We’re really, really concerned because it’s potentially just the tip of the iceberg,” Peter Leone told the Greensboro *News and Record* in July.<sup>11</sup> Leone, a state epidemiologist and UNC-CH professor of medicine, is actively stumping for more HIV awareness among the state’s youth and better testing policies at college and university student health services. Leone says that his hunch is that the college men who are contracting HIV know about the risks of unprotected sex yet they continue to engage in high risk activity with partners who may or may not be infected with HIV. For good reason, this behavior is often compared to Russian roulette.

When Leone reported these new infections to the CDC, that government health agency quickly dispatched a team of investigators to North Carolina to interview each newly

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<sup>8</sup> Gerberding, “Apathy and the AIDS Epidemic.”

<sup>9</sup> NC, *AIDS Case Report for 2002, North Carolina*, p 2.

<sup>10</sup> Peter Leone, “The Reemergence of HIV on College Campuses,” unpublished article, July 2003, and subsequent interviews.

<sup>11</sup> John Newsom, “HIV In N.C. College Students Increasing,” *News & Record*, July 31, 2003, B1.

infected student, attempting to learn more about the behaviors and circumstances that led to what Leone calls an “outbreak.”

Through these interviews, Leone has learned that the students recently infected with HIV are scattered throughout North Carolina. They’re connected through a social network of college campuses, dance clubs and Internet chat rooms where they’ve met many of their sexual partners. Their connections form a sexual network among men who have sex with men, but Leone and the CDC investigators are concerned that this network may also be connected to the vastly larger group of sexually active heterosexual men and women on the state’s college and university campuses. If so, HIV could spread among a larger group – college students – who haven’t yet seen high rates of HIV infection.

How HIV spreads is an important issue. Cohen often explains this to groups of journalists, students and anyone interested in sexually transmitted infections. Cohen uses the formula  $R_0 = \beta \Delta C$ . In this formula, the rate of transmission is determined by the product of beta, the efficiency of transmission;  $\Delta$ , the duration of infectiousness; and C, the number of people exposed through sexual contact to an infected person. Leone and his team in the department of infectious diseases, including Christopher Pilcher and Lisa Hightow, were studying the infectiousness of HIV when they uncovered the HIV cases among college students. The team of scientists, in a program called Screening and Tracing Active Transmission, was using a new technique for screening blood samples for the HIV virus to determine a better way to catch acute infection. Acute infection, as Pilcher’s research has shown, is a time when HIV is most easily spread.<sup>12</sup>

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<sup>12</sup> Christopher Pilcher et al., “Sexual transmission during the incubation period of primary HIV infection,” *JAMA*, 2001, 286:1713-1714.

Most common screening tests for HIV look for antibodies that the immune system makes to fight viruses, instead of the virus itself. Research indicates that the body makes relatively few HIV antibodies in the first five to six weeks after infection, so antibody screening tests during those first several weeks will be negative even though HIV is highly infectious at that time. It's only in week seven that the body makes enough HIV antibodies to turn the screening test, commonly known as the ELISA test, positive.

Leone says the real problem is that during this window – before the antibody test turns positive – an infected individual can spread HIV without knowing it. In this window, which infectious disease experts call “acute infection,” millions of copies of the HIV virus teem throughout the blood. This viral load is extremely dangerous because a person is so much more infectious than later, when the antibodies have brought the number of virus particles into check. “The risk of transmitting HIV to sexual partners is much higher,” says Leone. “Maybe anywhere from 10- to a 100-fold greater during those first three to six months than at any other time in their infection.”<sup>13</sup>

Leone and his team pooled the blood from North Carolina blood samples that had previously been examined with the antibody test. When they performed nucleic acid testing on the blood to search directly for the virus particles, they began to uncover the false negatives of the earlier tests. Of 8,155 at-risk individuals whose antibody tests had come back negative, five had acute HIV infection. Two of those five were college students. Leone was onto an important story.

In the course of this masters thesis project. I will report on the HIV outbreak among North Carolina college students. My report will be in the form of a narrative feature – a long,

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<sup>13</sup> Anton Zuiker, “HIV on NC Campuses,” *UNC-TV*, broadcast on “North Carolina Now” November 21, 2003, available online at <http://www.jomc.unc.edu/medicaljournalism/hiv1.ram>.

detailed magazine article that tells the stories of the people involved in this outbreak, including Peter Leone and one or two college men who contracted the virus. Narrative journalism is more than just reporting facts, and so in my article I will seek to capture emotion, discovery, conflict and more. Health education programs, state and campus testing policies, social mores and stigmas, and personal sexual choices are all called into question by this outbreak. If Schoofs is correct about HIV being a great story, then North Carolina has a good story for the telling. “The double stigma of racism and homophobia renders [black gay men] tragically vulnerable to disease,” Schoofs told the *Columbia Journalism Review*. “Hardly anyone is reporting on this, even though such fundamental social issues make the most compelling public-health journalism.”<sup>14</sup>

Literary journalism, or narrative journalism, is an appropriate way to tell this story. Narrative journalism is storytelling. It is different from the “inverted pyramid” style of reporting still taught in American journalism schools; in the inverted pyramid style, the most newsworthy or timely facts of a story are presented first, with subsequent facts of declining importance. In narrative journalism facts are interwoven between a descriptive narrative that often tugs at emotions, truths and personalities behind a story.

In the 1960s, Tom Wolfe and others popularized literary journalism; Wolfe called it New Journalism, and explained it as having “scene-by-scene construction, saturation reporting, third-person point of view, and a detailing of the status lives of the subjects,” writes Norma Sims in her excellent introduction to *Literary Journalism: A New Collection of the Best American Nonfiction*.<sup>15</sup> This type of journalism still stands on the bedrock principles

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<sup>14</sup> “Q & A on AIDS: Think Global, Write Local,” *Columbia Journalism Review*, May-June 2001, 12.

<sup>15</sup> Norma Sims, “The Art of Literary Journalism,” *Literary Journalism* (New York: Ballantine Books, 1995), 9.

of journalism – true details, accuracy of facts, attributed quotes. Sims also quotes former *Atlantic Monthly* editor Richard Todd, who said of literary journalism, “Voice and story are the only tools.” Story, explains Sims, “includes all the narrative techniques, as well as the intellectual substance of a tale.” Voice creates the impression of “something created, sculpted, authored by a particular spirit.”<sup>16</sup>

Other terms used to describe this writing include literary nonfiction and narrative nonfiction. Often, good narrative journalism will be just as compelling and instructive as a good novel. The only difference is that one story is fiction while the other is fact.

Literary journalism, writes Mark Kramer in a separate introduction to *Literary Journalism*, “has been a you-know-it-when-you-see-it form.”<sup>17</sup> Kramer is writer-in-residence at the Nieman Foundation, where he has organized the Nieman Conference on Narrative Journalism. In his introduction, he outlines his rules for literary journalists, which include immersion in a subject’s words and in background research; an “intimate voice” that is informal, frank and human; plain and spare style; and a disengaged and mobile stance, from which literary journalists tell stories from a “retrospective platform” and also addresses readers directly before turning back to the story.

The books and articles of Tracy Kidder exemplify these rules. Kidder is a narrative journalist who has won numerous awards, including the Pulitzer Prize. His recent book, *Mountains Beyond Mountains*, is a fascinating profile of the medical anthropologist Paul Farmer, who has dedicated his life’s work to promoting the health of the people of Haiti. (Kidder published an article about Farmer in *The New Yorker* in 2000.) Like other narrative

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<sup>16</sup> *Ibid.*

<sup>17</sup> Mark Kramer, “Breakable Rules for Literary Journalists,” *Literary Journalism* (New York: Ballantine Books, 1995), 22.



feature articles, Kidder’s profile of Farmer is seeded with references to Kidder himself, which serve to explain to the reader how, where and when Kidder observed Farmer. These references also serve as an indication of the level of Kidder’s immersion into Farmer’s life. Such references in narrative journalism help the reader to understand that the author has spent considerable time with the person and subject matter; they also help the reader to understand the limits of the reporting, for even a long narrative feature story can’t possibly be omniscient. While some critics of narrative journalism complain of the intrusion of the journalist into the story through first-person references, such explanation is important because it acknowledges that all reporting is by nature subjective.

**N**umerous reporters and journalists have written about communicable diseases and exotic new illnesses. Berton Roueché wrote the “Annals of Medicine” features for *The New Yorker*. His articles are riveting chronological reports of medical maladies and strange illnesses, in a style reminiscent of the fictional detective Joe Friday, all facts evenly expressed. Here’s one lead:

Around ten o'clock on the morning of Wednesday, March 4, 1964, a man named Donald Hoffman presented himself for treatment at the Student Health Clinic of Miami University, in Oxford, Ohio, some thirty miles northwest of Cincinnati.<sup>18</sup>

From there Roueché follows the patient and his doctors step by step until the riddle of his illness – Hoffman dies of anthrax – is solved. The physicians and clinicians who solve these riddles are medical detectives, sifting for clues, pulling arcane facts from their medical training and explaining the course of exotic diseases. (Roueché published his articles in multiple books; his first was *The Medical Detectives*.)<sup>19</sup>

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<sup>18</sup> Berton Roueché, *The Medical Detectives* (New York: Truman Talley Books/Plume, 1991), 179.

<sup>19</sup> *Ibid.*

*San Francisco Chronicle* reporter Randy Shilts was one of the first to cover the emerging AIDS epidemic in 1981. He wrote the seminal book, *And the Band Played On*, that continues to be an important chronicle of the early days of the epidemic.<sup>20</sup> In the book, Shilts details the unfolding public health crisis provoked by the AIDS crisis and the varying responses to it – by physicians, scientists, government officials, gay leaders, journalists. Shilts is deft at sticking blame where blame belongs. He asserts a slow response to AIDS in the early years of the epidemic allowed it to spiral out of control. Reporters, writes Shilts, “were willing to believe any story handed to them in a press release without the slightest inclination to discover whether the reported facts were true. Press-release journalism, out of vogue since the advent of Watergate-style investigative reporting, made a dashing comeback with the AIDS epidemic.”<sup>21</sup>

Howard Markel, a pediatrician and historian, reviewed Shilts’s book in a journal article about AIDS accounts. “While the book is a compelling narrative, it is an account filled with blame.” Markel writes, “The history of epidemics teaches us, again and again, that blame is a central component of these events, whether it be cast upon socially ostracized groups of people, water supplies, politics, or religious or cultural beliefs. A requirement of the journalist, and certainly the historian, however, is to explain human society, rather than to point fingers.”<sup>22</sup>

Laurie Garrett, a health reporter for *Newsday*, wrote two important books about infectious diseases and the state of public health systems around the world. *The Coming*

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<sup>20</sup> Randy Shilts, *And the Band Played On: Politics, People and the AIDS Epidemic* (New York: St. Martin’s Press, 1987).

<sup>21</sup> *Ibid.*, 183-184.

<sup>22</sup> Howard Markel, “Journals of the plague years: Documenting the history of AIDS epidemic in the United States,” *American Journal of Public Health*, Vol 91, No. 7, 1 July 2001, 1025.

*Plague* is a hefty book that was one of the first to chronicle how emerging and reemerging infectious diseases were causing a health crisis in the world.<sup>23</sup> *Betrayal of Trust*, another thick book with narrative chapters and extensive notes, investigated the collapse of the public health infrastructure.<sup>24</sup>

The work of epidemiologists can be fascinating and enlightening. These scientists study the causes, distribution, and control of disease in populations. *National Geographic* published an article titled “The Disease Detectives: Stalking the World’s Epidemics” by Peter Jaret.<sup>25</sup> He recounts how epidemiologists chased the cause of Lyme disease and how scientists concoct the annual flu vaccine. In that article, Jaret begins with the story of how English physician John Snow in 1849 pinpointed a public water pump as a vector of the deadly cholera epidemic raging throughout London. Snow’s deduction is commonly referenced in medical journalism articles about infectious diseases and epidemiology.

Another important epidemiology reference is Koch’s postulate.<sup>26</sup> Nobel Prize-winning German bacteriologist Robert Koch in 1890 devised the process by which an infectious agent is confirmed to be the cause of a disease. Those steps are:

- The suspected microbe must be found in all cases of the disease.
- That microbe must be isolated and grown in the laboratory.
- That microbe, when injected into a healthy animal or person, must cause symptoms of the disease.
- Microbes isolated from this new case must be identical to the original microbe.

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<sup>23</sup> Laurie Garrett, *The Coming Plague: Newly Emerging Diseases in a World Out of Balance* (New York: Farrar, Strauss Giroux, 1994).

<sup>24</sup> Laurie Garrett, *Betrayal of Trust: The Collapse of Global Public Health* (New York: Hyperion, 2000).

<sup>25</sup> Peter Jaret, “The Disease Detectives: Stalking the World’s Epidemics,” *National Geographic*, Vol 179 No 1, January 1991, 114-140.

<sup>26</sup> Garrett, *The Coming Plague*, 403.

During the epidemic of severe acute respiratory syndrome (SARS) in early 2003, few articles and reports in U.S. newspapers and magazines mentioned Koch's postulates. An important exception was Lawrence Altman in the *New York Times*.<sup>27</sup>

A more recent article in the *New York Times Magazine* is particularly relevant to my proposed project. In "Double Lives on the Down Low," Benoit Denizet-Lewis writes about African-American men who live straight lives with wives or girlfriends but who also engage in homosexual sex through a nightclub scene known as "the down low," or DL.<sup>28</sup> Benizet-Lewis reports that the CDC characterizes black men who have sex with men (MSM) as being twice as likely as non-black men to keep their MSM identity a secret; he also reports that a common explanation for this secretive behavior is an ingrained homophobia within the black community.

"There is a fair amount of racism within the white gay community that makes these guys not feel very comfortable in a lot of gay settings," says David Jolly, professor of health education at North Carolina Central University. "And I think there's still a fair amount of homophobia in the black community which makes it difficult for these guys to be upfront about the fact that they are having sex with other men, that they are gay."<sup>29</sup> But Raleigh *News & Observer* columnist Barry Saunders doesn't like the implications. "There's some truth there, but that absolves the men of responsibility," he wrote in a December 2, 2003 column, the day after World AIDS Day. "I'm guessing that most men having unprotected sex with men and women are just hedonists with no regard for the health concerns of others."<sup>30</sup>

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<sup>27</sup> Lawrence K. Altman, "Virus Called Mostly Under Control," *New York Times*, 12 April 2003, A6, (available from LexisNexis, accessed 15 January 2004).

<sup>28</sup> Benoit Denizet-Lewis, "Double Lives on the Down Low," *New York Times Magazine*, 3 August 2003, 28.

<sup>29</sup> Zuiker, "HIV on NC Campuses."

<sup>30</sup> Barry Saunders, "Protect, respect partners," *News & Observer*, 2 December 2003, B1.

It might not be so simple as that.

Columbia University professors Robert Klitzman and Ronald Bayer published a book about HIV infection and the truth, lies and deception that HIV-positive individuals exhibit. Their intent for *Mortal Secrets*, they write, “was to explore through narrative accounts how, in extreme cases of HIV and AIDS, people face questions of secrecy, morality and trust.”<sup>31</sup> The book includes numerous quotations from more than 75 men and women in response to questions about their sexual activity, how and when they were tested for HIV, and how honest about their HIV infection they were to their sexual partners. “Almost always, apprehension surrounded the process of getting tested – fears of being found out by others and of learning of dangers in one’s body,” write Klitzman and Bayer.

In my thesis project, I’ll explore these same fears. Similarly, I’ll explore the lies. Klitzman and Bayer found that their interview subjects quite often lied or dissembled about their HIV status.<sup>32</sup> “A lot of people do lie about their sexual behavior,” says North Carolina State University health educator Marianne Turnbull. “When one person might think they’re in a monogamous relationship, the other partner may be having relationships on the side.”<sup>33</sup> Like Leone, Turnbull expresses concern that the new HIV outbreak in North Carolina may be spreading because some men have sex with men and women.

Another useful book is “*You’re the First One I’ve Told*” by Duke University professor Kathryn Whetten-Goldstein and UNC-CH epidemiology student Trang Quyen

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<sup>31</sup> Robert Klitzman and Ronald Bayer, *Mortal Secrets: Truth and Lies in the Age of AIDS* (Baltimore: The Johns Hopkins University Press, 2003), 4.

<sup>32</sup> Howard Markel, “H.I.V. Secrecy Is Proving Deadly,” *New York Times*, 25 November 2003, D6.

<sup>33</sup> Zuiker, “HIV on NC Campuses.”

Nguyen.<sup>34</sup> Their book also includes oral history from individuals in the South, including North Carolina. The authors explore how inadequate health care in rural communities affects the treatment of HIV/AIDS and promotes the transmission of the virus. In its report on the changing demographics of AIDS in the U.S., the CDC notes that North Carolina is one of the 29 states that saw increases in the incidence of HIV over the last few years.<sup>35</sup>

As the numbers of AIDS cases have gone up in the last 20 years, the number of stories about HIV/AIDS in American newspapers and on television has gone down, according to a quantitative study of AIDS journalism from 1981 to 2002 produced by The Kaiser Family Foundation and Princeton Survey Research Associates International. The study results were published as a supplement to the March/April 2004 issue of *Columbia Journalism Review*, and they are enlightening. Addressing the argument that “AIDS fatigue” has set in, the authors of the study write, “The challenge for journalists covering HIV/AIDS is to find new ways to keep their audience engaged in a story that may not meet editorial standards for ‘news’ as clearly as it once did.”<sup>36</sup> They later write that “though AIDS is now the leading cause of death among African Americans ages 25 to 44, and they represent the majority of new HIV infections, only 2% of stories during this time period focused on African Americans.”

A recent anthology of AIDS journalism, *While the World Sleeps: Writing from the First Twenty Years of the Global AIDS Plague*, is an excellent collection of some of the best

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<sup>34</sup> Kathryn Whetten-Goldstein and Trang Quyen Nguyen, *“You’re the First One I’ve Told”*: *New Faces of HIV in the South* (New Brunswick, New Jersey: Rutgers University Press, 2002).

<sup>35</sup> CDC, “Advancing HIV Prevention: New Strategies for a Changing Epidemic – United States, 2003,” *Morbidity and Mortality Weekly Report*, Vol 52 No 15, 18 April 2003.

<sup>36</sup> Mollyann Brodie et al., “AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002, supplement to *Columbia Journalism Review*, March/April 2004, available online at <http://www.kff.org/kaiserpolls/7023.cfm> (accessed 9 March 2004).

stories and articles about AIDS.<sup>37</sup> It will no doubt serve as an important college text for other students to use in understanding the media coverage of the epidemic.

Some other examples of writing about HIV/AIDS both in the U.S. and globally have been particularly helpful to me in preparing to complete a narrative feature story about HIV in North Carolina.

Mark Schoofs won a Pulitzer Prize for international reporting for “AIDS: The Agony of Africa,” a series of articles about AIDS in Africa for the *Village Voice* (Schoofs is now with *The Wall Street Journal*).<sup>38</sup> Schoofs is a deft reporter. His articles are compelling for their breadth of sources, statistics and gripping stories. Part one begins with this narrative lead:

They didn't call Arthur Chinaka out of the classroom. The principal and Arthur's uncle Simon waited until the day's exams were done before breaking the news: Arthur's father, his body wracked with pneumonia, had finally died of AIDS. They were worried that Arthur would panic, but at 17 years old, he didn't. He still had two days of tests, so while his father lay in the morgue, Arthur finished his exams.<sup>39</sup>

Schoofs's series continues the narrative and is quite informative and comprehensive.

Liz Doup, a health reporter for the *South Florida Sun-Sentinel*, wrote, edited and produced a 24-page insert about AIDS in South Florida that focused on the faces and stories of the people involved in the epidemic.<sup>40</sup> The pictures of each of the subjects combine with the personal writing for an emotional and enlightening package.

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<sup>37</sup> Chris Bull, ed., *While the World Sleeps: Writing from the First Twenty Years of the Global AIDS Plague*. New York: Thunder's Mouth Press, 2003.

<sup>38</sup> Mark Schoofs, “AIDS: The Agony of Africa,” *The Village Voice*, 1999 and 2000, available online at <http://www.villagevoice.com/specials/africa/> (accessed 7 April 2004).

<sup>39</sup> *Ibid.*, “Part 1: The Virus Creates a Generation of Orphans,” 3-9 November 1999.

<sup>40</sup> Liz Doup, “AIDS In South Florida,” *South Florida Sun-Sentinel*, 8 June 2003.

Michael Specter, Samantha Power and Tracy Kidder have all written long, narrative profiles in *The New Yorker* about individuals fighting the AIDS epidemic: Specter on New York AIDS activist Larry Kramer,<sup>41</sup> Power on South African AIDS activist Zackie Achmat,<sup>42</sup> and Kidder on Harvard physician Paul Farmer, who is an expert on AIDS in Haiti.<sup>43</sup> These three in-depth profiles introduce and record distinct individuals, of course, but they also dig into the issues that link these men and all the other millions of men and women fighting the HIV/AIDS epidemic. Long-form narrative journalism is particularly useful for telling stories about HIV/AIDS, because HIV/AIDS is such a complex topic – the science of HIV is complex, the emotions are deep, the deaths are widespread, the politics so convoluted. One need only hold Randy Shilts’s hefty book – which covered only the first five years of the epidemic in mainly the U.S. – to understand the amount of material to work with. Narrative journalism uses storytelling to report, inform and energize.

## **Method**

To provide background for my article, I’ll research the medical literature and survey newspaper, magazine and online journalism articles about HIV/AIDS. In addition, I’ll conduct extensive interviews with medical professionals, public health specialists, bench scientists, persons with HIV and others with an interest or role in promoting HIV awareness. Because of the stigma associated with HIV/AIDS, and especially surrounding the new outbreak of HIV among African-American men who have sex with men, I will use pseudonyms for sources who request that their real names not be used.

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<sup>41</sup> Michael Specter, “Public Nuisance,” *The New Yorker*, 13 May 2002, 56, available online at [http://www.michaelspecter.com/ny/2002/2002\\_05\\_13\\_kramer.html](http://www.michaelspecter.com/ny/2002/2002_05_13_kramer.html) (accessed 7 April 2004).

<sup>42</sup> Samantha Power, “The AIDS Rebel,” *The New Yorker*, 19 May 2003, 54.

<sup>43</sup> Tracy Kidder, “The Good Doctor,” *The New Yorker*, 10 July 2000, 40.



## **Medium**

This report will be a single narrative feature article of 6000 words developed in four parts. It will follow the model of select *New Yorker* features and be intended for an educated readership both in North Carolina and nationally. In order to reach a national audience, I will contextualize the story with the national HIV picture.

I intend to submit this report for publication in a national magazine to be determined, in time for publication coincident with the International AIDS Conference in mid-July 2004.

In addition, I will use my website [www.medicaljournalism.info](http://www.medicaljournalism.info) to post links to websites, documents, resources and individuals that I encounter in the course of my reporting this article. My weblogging about HIV in North Carolina, the U.S. and globally will serve as a record of my research but, more importantly, also as a resource to other journalists covering this “great story,” as Schoofs calls it.

## **Availability of Resources**

I expect most resources necessary for this report will be readily available within North Carolina. All research and literature is accessible through the UNC library databases and/or government sources. Some interviews with experts and scientists will be conducted by telephone. Incidental costs of about \$500 are expected and will be requested through my Park Fellowship research funds. Additionally, I will attend two conferences that will provide guidance and direction to this project:

- ⊙ The Nieman Conference on Narrative Journalism, December 2003 – This is a gathering of journalists committed to narrative reporting, and I will have access to

Pulitzer Prize-winners Jon Franklin and Jacqui Banaszynski,<sup>44</sup> in addition to other excellent writers and reporters.

- ⊙ Association of Health Care Journalists Convention, March 2004 – This is a gathering of professional health reporters, and will provide access to numerous journalists who cover HIV/AIDS in the U.S.

## **Report Outline**

This report will be a 6000-word narrative magazine feature article, divided into four parts of roughly 1500 words each:

- ⊙ The story of a minority male college student and how he contracted HIV. This report will introduce the N.C. epidemic, explore the “down low” culture and touch on social stigma, and lead into the profile of Leone.
- ⊙ A profile of Peter Leone, M.D. and how he and his team discovered the N.C. HIV outbreak: a review of his research with Christopher Pilcher and Lisa Hightow, the “aha” moment where two new HIV cases flagged their attention to the outbreak; an explanation of HIV in N.C. past and present, including prevalence, incidence, transmission modes and mortality rates.
- ⊙ An explanation of the science of HIV testing: a review of the epidemiology of transmission, the science of acute infection and a discussion of antibody and ELISA (enzyme-linked immunoadsorbent assay) testing.
- ⊙ A review of university health service testing policies that will lead into an issues exploration of the public health measures for treating and preventing HIV in North

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<sup>44</sup> *St. Paul Pioneer Press Dispatch* reporter Banaszynski won a 1988 Pulitzer Prize for “AIDS in the Heartland,” her series of articles about a Minnesota farmer who was dying of AIDS. That series is unavailable from electronic databases.

Carolina. Compare and contrast to global efforts, past N.C. efforts. Discuss how the presence of CDC investigators changes how state officials think about HIV in North Carolina. If appropriate, I'll discuss research into an HIV vaccine and antiretroviral therapies at area universities and other laboratories.

## **Committee**

As required, this thesis project will be directed and advised by a faculty committee.

Committee chairman is **Thomas Linden**, M.D., director of the Medical Journalism Program in the School of Journalism and Mass Communication; committee members are **Neil Caudle**, associate vice chancellor of research and economic development and editor of *Endeavors Magazine*, and **Andrew Kaplan**, M.D., associate professor of medicine, department of microbiology and immunology, UNC School of Medicine.

# Back to School

In North Carolina, researchers went looking for new cases of HIV infection.

What they found was a surprising, though not unexpected, outbreak

By Anton Zuiker

**O**n a Friday morning in February 2003, medical researchers at the University of North Carolina at Chapel Hill learned over a conference call that the state health department, using a pioneering screening protocol, had found new cases of HIV infection in two men. Both individuals had recently visited public health clinics to be tested for HIV, but had been told that an antibody test found no sign of the virus in their blood. In a quirk of testing, though, they *were* HIV-positive, but at such an early stage of infection that their bodies had yet to make antibodies that could be detected by the normal screening test. Their blood had been passed to the state lab as part of a program called North Carolina Screening and Tracing of Acute Transmission (STAT), an effort to find such early infections. Lab technicians had retested the blood samples. Case number one, the state investigators reported over the telephone, was a university student from a Raleigh-area campus. Case number two, they also mentioned, was another university student from a Raleigh-area campus.

That raised eyebrows in the UNC conference room. “This is not good,” Peter Leone said to himself. Leone, an infectious diseases physician and medical director of the state HIV/STD Prevention and Care Branch, had treated AIDS patients in North Carolina since

1985. He had recently studied an outbreak of syphilis in 2001 that also involved college students, and he was attuned to sexually transmitted diseases in the state. Lisa Hightow, a physician working as a research fellow with Leone, was also in the room, and she met Leone's eyes with similar alarm.

Of course, college students are no more protected from the human immunodeficiency virus than other individuals, and yet college campuses have been seemingly spared large numbers of cases of HIV, the virus that causes AIDS. College students still have sex, and don't always use safe sex measures that can prevent transmission of HIV. Unprotected sex – sex without using condoms – is the leading cause of HIV transmission, according to the Centers for Disease Control and Prevention (CDC). A two-phase seroprevalence survey begun in 1988 by the CDC estimated that just two-tenths of one percent, or one in 500, of the nation's then 13 million college students were infected with HIV. In 1994, the CDC's Scott Holmberg warned that the low prevalence, though reassuring, shouldn't induce complacency, but the CDC discontinued its college surveillance and focused attention and funds for studies of other more at-risk populations such as prison inmates and African-American women.

That 1988 college survey was the only substantial research Leone and Hightow could draw on when considering HIV among North Carolina's students. There had been no documented outbreak of HIV on a college campus anywhere in the U.S., they said, an assertion echoed by Lisa Fitzpatrick, a CDC medical epidemiologist. The fact that no outbreak had been described or studied, though, was only part of the story. Leone had treated HIV-infected college students before, and even Fitzpatrick's boss at CDC, Thena Durham, deputy director of policy in the National Center for HIV, STD and TB Prevention, told me HIV on college campuses wasn't something new. "It's something we've not focused on," she

said. “As you know, our approach to HIV is changing.” Where before 2003 CDC had a generalized approach to HIV prevention – spreading the word among all Americans – the agency in April 2003 unveiled a new, targeted approach. Now, said Durham, CDC is targeting individuals who are already positive, so they don’t spread HIV further, and also targeting those most at risk for becoming infected. North Carolina was about to give CDC an opportunity to put that new approach to work.

A few days after that conference call, Chris Pilcher, another researcher who was in the STAT meeting with Leone and Hightow, mentioned the two cases to an assistant at the Wake County STD clinic, where Leone had once been the director and now Pilcher was staff physician. The assistant said he’d recently treated a half dozen other college students for HIV infection. Pilcher reported back to the group, where there was now more interest in investigating the cases. Hightow got the nod to explore the connections between the infected men – were they just a coincidence, or part of a larger outbreak among a new subpopulation, the tip of an iceberg? “From there, it spun out of control,” said Hightow. She spent the next few months in a room full of filing cabinets, reading through hundreds of confidential case records of the men and women who had been told in the last few years that they were HIV-positive. She was looking for any indication that some of these people were students at colleges or universities in and around the state capital. Sure enough, she began to find them, and two became five, five became seven, seven became twelve.

The North Carolina health department divides the state into eight regional and satellite offices. At first, Hightow sifted through the files of the region around Raleigh, filling a page of her yellow legal notepad with a sketch of how those HIV-infected college students were clustered at certain schools. Over the next months, she expanded her review to include

seven of the eight regions (the western region has an overall low annual incidence of HIV) and also looked back to January 2000.

By August 2003, Hightow's tally was up to 56 cases from more than 30 college and university campuses across the state. In February 2004 – a year after that first conference call – the number had grown to 84 students from 37 campuses in North Carolina, as well as additional students at seven other colleges in West Virginia, Virginia, South Carolina, Florida and Georgia. Having reviewed the files from those HIV tests administered at the state's network of public clinics and hospitals, Hightow could document six HIV cases among male college students ages 18 to 30 in 2000; 19 cases in 2001; 29 in 2002 and 30 in 2003. (She also found one female college student who was HIV-positive.) Hightow and Leone improved her cluster sketches, which now provided a map of the sexual networks showing how college campuses were connected by the students and their sexual partners. One such network connected at least 15 colleges and universities, a detail that suggested how HIV could have skipped across the state.

The UNC-CH team and their counterparts at the state HIV/STD Prevention and Care Branch were even more alarmed now, for they had found evidence of what seemed to be the first U.S. college HIV outbreak. “We don't know what happened before 2000,” said Hightow, but the numbers over the four years since then “indicate a true increase.” She and the researchers were also worried that the numbers would continue to rise, and that more female college students would become infected.

Since 1990, North Carolina state law has required all positive HIV tests be reported to the state division of public health, which releases quarterly and annual figures for HIV incidence, as well as the numbers of persons with AIDS (a person can be infected with HIV

for years before the infection progresses to AIDS). In North Carolina since 1998, the numbers of new cases of HIV have increased in all but one year; from 2002 to 2003, the number jumped from 1,692 new cases to 2,100, an increase that was the largest since 1995.

But it was the college numbers that would grab the attention of public health officials and the media, and the news that HIV was infecting college students would spark discussion among campus health services, student peer educators and university administrators, especially among the historically black colleges and universities in the state. Of the 84 college cases, 73 were African-American students, part of a larger disparity in North Carolina, where non-Hispanic blacks were 22 percent of the population in 2003 yet made up 67 percent of the new cases of HIV. (AIDS advocates cautioned that the high ratio of black-to-white college cases might be misleading, since Hightow's numbers came only from the public clinics in the state, which disproportionately serve a poorer, minority population.)

In summer 2003, Hightow, Pilcher and Leone presented their findings at public health and scientific conferences in Atlanta and San Diego, and Leone began to talk up his concern that this outbreak might extend deeper than their preliminary exploration had already shown. Officials in the health division were also alarmed, and in August 2003, State Epidemiologist Jeff Engel asked the CDC to send a team of Epidemic Intelligence Service (EIS) investigators to help determine the behavioral roots of the college-based HIV cases.

**C**ollege-based HIV “just wasn’t on the radar screen,” said Lisa Fitzpatrick, director of the CDC’s Minority HIV/AIDS Research Initiative. College students essentially are



adolescents, she said, and the results from that 1988 CDC survey that looked for positive cases of HIV on college campuses were so low that subsequent research into adolescent risk behaviors didn't bother to explore risk behaviors of college-aged adults.

Fitzpatrick led a CDC team that came to North Carolina for a three-month investigation and conducted a case-control study to try to determine the risk factors for acquiring HIV. Her team interviewed 18 of the HIV-positive college students, as well as 19 HIV-negative college students and 15 HIV-negative men under age 30 who weren't in college. The team found these negative controls, who were black males age 18 to 30 who had had sex with a man in the last 12 months, in gay dance clubs in the state's three largest cities. Acknowledging the stigma associated with HIV in the African-American community, Fitzpatrick and the EIS investigators offered to interview the HIV-positive college students on their own terms, which included meeting at a picnic table in the middle of a city park and in a car in a Wal-Mart parking lot.

After interviews with each of the 52 cases and controls, Fitzpatrick determined that just one-third of the college students (cases and college controls) met their sexual partners on campus. Nightclubs and the Internet were more frequent meeting places. Fitzpatrick also learned that the students – both HIV-positive and HIV-negative – were less likely to identify themselves as being gay and were less open about their sexual preferences than were the non-college men who were HIV-positive, 80 percent of whom self-identified as gay.

“These young black men were at risk [for contracting HIV], and it really didn't matter if they were in college or not in college,” said Fitzpatrick. “While it's fascinating that this was detected because of the college factor, what's even more fascinating to me is that you could take the college factor away and see that everyone is pretty much taking the same

risk.” She pointed out that in North Carolina, men age 30 to 49 have the highest rate of infection with an annual incidence of 63 for every 100,000 men in that age range, compared with an annual incidence of 38 for men age 20 to 29.

I asked James Curran, dean of the Rollins School of Public Health at Emory University, to review Fitzpatrick’s research abstract that she presented to the 11th Conference on Retroviruses and Opportunistic Infections in San Francisco in February 2004. Curran worked for the CDC when AIDS first came to the attention of officials there, and he led the early CDC efforts to understand the AIDS epidemic. “It is not surprising that HIV+ college students are more likely to be gay and less likely to be injecting drug users or cocaine users,” he responded by e-mail. “This is the history of the epidemic.”

A. Cornelius Baker wasn’t surprised to hear of the North Carolina college increase either. Baker is executive director of the Whitman-Walker Clinic, a Washington D.C.-area, community-based gay men’s health clinic that began responding to the AIDS epidemic in 1983. “We know HIV is spread among young adults, that it’s having a tremendous impact on African Americans, and that it’s increasingly widespread in the South, particularly outside the urban centers,” he told me on the telephone one afternoon. And it wasn’t new for that pattern to be also having an impact on men who have sex with men, including those who don’t identify themselves as gay, he said. That it was also happening to college students “just confirms all the evidence of the last 20 years of this epidemic, that HIV can afflict anyone,” he said.

A 2001 CDC study had determined that HIV incidence rates were up among men who have sex with men, or MSM. This is the fine distinction that’s evolved to designate homosexual behavior, since it turns out that many men who don’t think of themselves as gay

do have sex with other men. And that taps into a popular, but inadequately studied, cultural phenomenon known as “living on the down low.” Among African Americans, this has come to mean a man who has public relationships with women but private trysts with men. It’s a charged and sensitive topic that few want to discuss. Besides, there’s scarcity of data to support any conclusions, say those who study bisexuality among African-American men.

Greg Millet, a behavioral scientist with the CDC, reviewed the “down low” phenomenon at the 2004 retrovirus conference. (A webcast of his presentation is available online at <http://www.retroconference.org/2004/home.htm>.) There are more questions than answers when it comes to “down low,” he said. “The DL debate is replete with references to men who deny their true sexual desire and in the process endanger the lives of black women. But sexuality is not that simple.” He explained three key concepts: sexual orientation, identity and behavior. “Sexual orientation is to whom you are attracted. Sexual identity is how you describe yourself to yourself and to others, and sexual behavior is with whom you have sex. In the least complicated of all worlds, a man attracted only to men would have a homosexual orientation, a gay identity and sleep only with men. But we don’t live in that world, and there are numerable and congruent combinations, including men whose sexual orientation might be homosexual, identify as straight and sleep with women and men.”

Fitzpatrick pointed out that to find men for her case control study of the North Carolina college outbreak, she went to gay nightclubs. There, she said, the men weren’t hiding their sexuality as men on the down low are assumed to be doing. (The design of this study may very well have missed other young men who engage in risky sexual behavior – with men and with women – but who shy away from gay bars.) Her study indicated that only 10 percent of all the study participants reported casual or steady female partners. Hightow’s

subsequent review of all 84 cases, though, suggested that 40 percent of them had admitted to having sex with both male and female partners. As Leone and Hightow understood the increase in the college cases, HIV was spreading among the men, but they also worried that the men who admitted to having had sex with men and women would be the bridge that could introduce HIV to the heterosexual college population.

Fitzpatrick expected her case-control study to be published in the CDC's *Morbidity and Mortality Weekly Report*; Hightow submitted her write-up of the college outbreak to *The New England Journal of Medicine* and *The Journal of the American Medical Association*, but reviewers for both journals rejected the study for publication. "They didn't think the numbers were significant, and they questioned what was new about [HIV among gay men]," Leone told me over the telephone one evening in March. Six weeks earlier, he had called me and obliquely referred to interpersonal tensions among the team of UNC researchers as they juggled their egos, personal agendas, ideas for papers and hopes for publication. "We can't lose sight of the goal, which is preventing transmission of HIV," he said.

In the absence of a published peer-reviewed article, others were also questioning the significance of the study. Jim Shamp, a health reporter for the Durham *Herald-Sun* who has written about Leone's work on college-based HIV, was troubled by the lack of data previous to 2000, and suggested Leone's use of the term "outbreak" for the four-year increase was inappropriate unless the epidemiologists could determine the historical trends in HIV incidence among college students in North Carolina. In epidemiology, an outbreak is a sudden increase in the occurrence of a disease in a short period of time. Similarly, Dean Curran of Emory University said the data were insufficient to know if the 84 cases over four years represented a true increase. Still, Curran wrote to me that calling attention to the

problem of HIV transmission among gay and bisexual African-American men in college was important. Shamp agreed.

Leone had vowed to me that he would “go down in flames” in order to spread the news of HIV infections among college students. “If we’re only concerned with numbers, we’d just be putting out [academic] papers,” he said, explaining his motivation for getting the story into state and national media. Science and medical journals hold journalists to strict embargo dates so that journalists won’t report on a study before it comes out in the journal. Leone’s talking publicly about his study before the article was accepted for publication may have been a factor in the medical journals rejecting his article. But the strategy of talking publicly was working with the national media. The *New York Times*, among other papers, quoted Leone in a front-page April 2004 article about HIV among African-American women.

When I told him that the March 24/31, 2004 issue of *JAMA* included a news item about the North Carolina increase, Leone was pleasantly surprised. For her part, Hightow was mad. The reviewers hadn’t questioned the validity of the statistics or the analysis, she said, and now the college increase was important enough to be covered in the journal’s news section but not important enough to be considered for the news-making original studies section. She planned to submit an updated paper about the college cases to *The Lancet*, another highly regarded medical journal, and then “go down the ranks” of the rest of the journals until it got published.

**P**atrick Lee once carried with him a snapshot showing his mother and grandmother side-by-side. Often, he’d pull the picture from his pocket, remember that he’d forgotten to tell his mom or grandma something important, and reach for the telephone to call them. He

said his family was close, and they could talk about almost anything. With the telephone in hand, though, he'd remember that his grandmother had died just three days after his mother passed away, and the snapshot of them lying in state at their double funeral in Miami in 2000 was a reminder that they weren't around to take his calls.

Lee's grandmother had been a nurse. His mother had been a nurse, too. But one of the few things the family didn't talk about was sex and the threat of sexually transmitted diseases. In the summer of 1989, between his freshman and sophomore years at Mercer University in Macon, Georgia, Lee learned he was HIV-positive.

"That's one reason I say that this [North Carolina college] epidemic is not new. We're just getting a handle on it. Do the math," he said. "We always heard that the age people were dying of AIDS was the range 29 to 40." And since a person can be infected with HIV for up to 10 years before AIDS symptoms begin, that puts those individuals at college age when they contracted HIV. (A. Cornelius Baker, of the Whitman-Walker Clinic, seconded this when he mentioned to me that the late-progression infections his clinic sees in African Americans in their 30s suggests the patients were college age when they became infected.)

After college, Lee got a job with the United Way of Greater Greensboro and began to volunteer with the Triad Health Project, where he later joined the board of directors. Serving others helped him face his own infection. Still, he kept quiet about it.

Then, he wasn't alone. In 1995, his mother found out she was infected with HIV. That news prompted Lee to get involved in AIDS advocacy, so he began to work with the Eastern Triad HIV Consortium. In 1997, another bombshell – his older brother learned that he, too, was positive. "HIV hit a family that shouldn't have been hit," said Lee, ruing the

silence that had put them all at risk. His mother quickly became ill with AIDS. “Unlike me, she didn’t have time to think about it, didn’t have a healthy period like me.” He recalled that the strength she had in fighting her illness showed him he had a profound strength, too. He began to speak about his HIV status, although selectively. “There’s a view that HIV-positive people should speak about it anywhere and everywhere,” he told me. But he said he also recognizes a public perception that HIV infection equates to diminished mental capacity – that HIV-positive individuals are poor and less intelligent. “I like for people to judge me on my abilities rather than perceived disabilities,” he said. Perhaps to prove the point, he earned a law degree from the University of North Carolina at Chapel Hill. Law school also gave him something besides HIV to focus on. He saw his degree as a “way out of social service. I wanted to practice law and not have to worry about bills anymore.” But he’s kept with AIDS advocacy, working recently for the N.C. Council for Positive Living. In March, he took a new job with the Piedmont HIV Health Care Consortium. (He told me that he’s refused to take the bar exam because the application requires him to sign a waiver giving the Board of Law Examiners access to all his medical records. That waiver states that it allows the board to determine the “moral character, professional reputation and fitness for the practice of law” of the future attorney.)

As details emerged of the increase in HIV cases on North Carolina college campuses, Lee spoke adamantly about removing the labels – gay, MSM, down-low, men of color – from the discussion. He wanted others to know that any person can potentially contract HIV. The way to break through the stigma of HIV, I heard him say on numerous occasions, is to make HIV commonplace – “HIV” should fall off our lips, he said. “We need to increase the fear of catching it, and decrease the fear of people living with it. It’s a hard line to toe.”

In March 2004, Lee spoke at the opening session of the Stomp Out HIV/STDs conference, which was organized by state officials to bring together students from the state's 12 historically black colleges and universities. Jonathan Perry, a student from Charlotte, introduced Lee at that conference. Perry is a tall, thin young man, and when he stood at the podium and began to speak, the audience couldn't quite hear him, so he pulled the microphone up to his face and shouted, "Can you hear me now?" He asked the students to look beside them. "The person sitting next to you is what a person with HIV looks like," he started. There were laughs from among the 100 students, and to me Jonathan sounded miffed. "It's not a laughing matter. AIDS is the number one cause of death for African Americans between the ages of 25 and 54. Every hour seven African Americans die of AIDS." His voice changed, becoming less sure but more personal.

"I got to Johnson C. Smith University in 2000. In 2001, I found out I was HIV positive. I thought that I was 'supah,' that I couldn't get it," he said. Perry told them he was openly gay. He said he refers people who have problems with his sexuality to "see my creator." Jonathan and his partner were having protected sex one night, he said, but the condom broke. When Jonathan went for his HIV test results, he had a smile on his face the entire time, but that smile was a facade. "My results were so positive," he told a waiting friend, and he knew his life had changed. The normally crystalline Charlotte skyline didn't look beautiful that day, he recalled. He became depressed, his grades dropped and his relationships suffered. Telling his mother was tough. "What was harder was my mother's response: 'That's what you get for being grown.'"

Perry had the crowd's attention now. His testimony was a powerful way to open a conference meant to reinforce the messages of HIV prevention that these students, most of



whom were peer counselors, wanted to make on their respective campuses. “I’m not ashamed to say I’m HIV positive. HIV is not a gay issue. It’s not a straight issue. It’s not a them issue. It’s a we issue.” At that, the students applauded him. The next night, after a local television station had featured Jonathan in a newscast, he was checking his email when an unsolicited instant message popped up. A young man he’d never met wrote to commend him for his courage in speaking about his sexuality and his HIV status.

**B**y March 2004, Peter Leone had been quoted in dozens of news stories about the North Carolina college outbreak. Yet he was bothered by the skepticism given to his team’s findings. “People say, ‘well, it’s only 84.’ It’s 84 and the numbers are going up. It’s 84 college students. It’s 84 folks no one recognized before. Instead of talking about all the other things that are out there, why don’t we deal with something we can actually have an impact on while we still have time to do something?”

This was an eerie echo of similar questions from the early days of the AIDS epidemic in the U.S., a topsy-turvy time chronicled in Randy Shilts’s seminal book *And the Band Played On*. Shilts implicates the silences of the compassion-deficient Reagan Administration and a squeamish press corps unwilling to question the response of federal health officials.

The lack of response to AIDS by the Reagan Administration allowed the epidemic to grow, said Leone. “I see the same pattern happening again with the college students. I can’t get over it.” He paused. “The numbers are sort of interesting. When we had two, few of us thought it was a big deal. We got into arguments with people when we got up to seven. When we got to twelve, people still didn’t believe it. Twenty-seven, we presented it at a national conference. It got about 48 hours of news and it died. When we got up to 54, publications

started paying attention to it, and we got an Epi-Aid [epidemic-aid field investigation by the CDC]. When we got up to 84, it's been all the news for the last six weeks. Was it any less of a problem when we only recognized seven? No. I thought if we had only one case we should be asking a lot of questions and paying attention to it."

Soon after those first two cases came to light, Leone informed his UNC-CH boss, Mike Cohen, who is the director of the Center for Infectious Diseases at the UNC-CH School of Medicine. Cohen let the university chancellor know about the possibility HIV was spreading among college students. Leone's other bosses in the state health department were "less than thrilled with the fact that it went from me to the chancellor's office." Some of Leone's state colleagues wanted a slower, more methodical approach to sharing the news, he said. "We were still struggling very early on in this thing to get people to recognize that this was a real deal. As a group, we recognized this starting with two. When we saw seven, I said we've got a big problem. I've been saying this for months. It doesn't give any satisfaction that now we're at 84 that the rest of us were right."

As 2004 began, Leone was hammering away, trying to build a case that the increasing numbers needed much more attention because of what it portended. He told me he's not particularly assertive, and that he's a free thinker who doesn't like being confined in a box. I asked him how he decided to focus his work on HIV.

Leone was brought up in a conservative Italian-American family headed by a Pentecostal minister. (On the corner of Leone's desk was a Jesus action figure, a votive candle made by his daughter and a snow globe in which a sister-in-law had inserted a picture of Pope John Paul II. "But I'm not Catholic," Leone laughed.) He had a cousin in New York City who died of AIDS early in the epidemic, but one of his first patients had more of an

impact on him. During a fellowship at Wake Forest University in 1985, he met Selden Cundiff, who'd come home to Winston-Salem from New York City after learning he had AIDS. Each week, Cundiff would read the *New York Times* while waiting for his appointment with Leone and then leave the paper for Leone to read. Cundiff's CD4 count – a measure of certain immune system cells that fight infection – “bottomed out,” and he came to the hospital wracked with pain. Cundiff approached his painful illness and coming death with courage and grace, said Leone. At the time, Leone was mainly a bench scientist focused on neutrophils, a type of white blood cell, but Cundiff had inspired him to focus his career on clinical care. In January 2004, Leone visited Winston-Salem for the tenth anniversary of the founding of Holly Haven, an AIDS hospice he helped start as a tribute to Cundiff.

Cundiff helped Leone get over his own homophobia. He came to understand that it was OK to be heterosexual and to have people think he might be gay, which seemed to happen quite a bit in the early years of the AIDS epidemic, when often the only doctors who would treat gay men were gay doctors. “Part of being involved with the HIV epidemic is being willing to take on some of the stigma associated with the disease,” he told me. He was a white, single heterosexual male who was taking care of HIV patients in the mid-80s, a time when many thought the virus could be easily spread to caregivers. “Not that it matters whether I'm straight or single or gay or whatever. I realized that, for me, part of this was being able to empathize and to take on societal issues of what people might think.”

In one of my conversations with Leone, I asked him to anthropomorphize the virus, to imagine what HIV was thinking as it infected college students. Leone answered that HIV was already looking for new targets. “‘How can I get to the next group in the society and go below radar.’ It's an opportunistic infection. It seeks out where the social fabric is a little

frayed, those folks that aren't necessarily as connected to the mainstream, and disproportionately impacts those who are more marginalized or more traumatized in the society. HIV is a vicious virus in terms of its ability to avoid detection in the immune system. And it also follows the fault lines in the society and splits things wide open. It hits on all those hot-button issues that we don't deal with very well – race, sexual orientation, sex in and of itself. But it may have miscalculated on this one,” he said, suggesting the African-American community, with its show of support for the Stomp Out conference, was beginning to embrace young men and their sexuality and cement the fault lines.

**H**ow researchers discovered the college outbreak, said Leone, is an example of the power of the state's acute HIV screening program that tests for the earliest signs of HIV infection. This is a program that has epidemiologists and HIV caregivers excited, not the least Christopher Pilcher.

I went to see Pilcher shortly after he returned from presenting research about the North Carolina college HIV increase to the 11<sup>th</sup> Conference on Retroviruses and Opportunistic Infections in San Francisco. Along with other AIDS specialists at UNC-CH, Pilcher works from a former Chapel Hill church that's been converted for office use. I found him in his small, spare office in the choir loft. He was dressed in a grey suit, with a short black beard, and he sat back in his chair, his legs out in front him lengthwise in the office. On the wall next to a picture of a sailboat were his Harvard undergraduate diploma and Duke University medical degree.

Between graduating from Harvard and entering Duke, Pilcher had been a Peace Corps Volunteer in Congo, where he'd developed an interest in international infectious diseases. At

UNC-CH, he met Charlie van der Horst, a professor of medicine who'd been an infectious diseases resident in a New York hospital in 1981 when the first AIDS patients fell ill. From 1985 on, van der Horst had worked in North Carolina to build the state's network of AIDS clinics and research successes. Then, spurred by what he'd seen in South Africa when he attended the International AIDS Conference, he abruptly changed course to work in Malawi, where 15 percent of the population is infected with HIV, according to UNAIDS estimates. Another Carolina AIDS expert, Joe Eron, mentored Pilcher. He allowed Pilcher to oversee a study of acutely infected patients.

As physicians and virologists have learned about how HIV infects the body, they've come to understand the stages of HIV infection and AIDS illness. Acute infection occurs during the first weeks of HIV infection. When HIV invades the body, the virus seeks out CD4+ cells, a type of white blood cell that the immune system makes to destroy such invaders. But HIV has the pernicious ability to grab onto CD4+ cells and get inside, where HIV turns the cells into factories to make new viruses. Within days, billions of virus copies swarm throughout the bloodstream. The body's immune system fights with its other weapons and begins to produce antibodies that neutralize the virus. Eventually, the number of HIV particles in the bloodstream falls low enough for the body to check the virus, though not completely eradicate it. The acute, or primary, phase of infection ends after four to six months. A person often will live for up to 10 years before HIV again overwhelms the body as opportunistic infections creep in, leading to death. This last stage is AIDS.

People infected with HIV do get sick during acute infection, but because the symptoms are similar to other illnesses, many doctors misdiagnose patients as having mononucleosis or send patients home with assurances that these flu-like symptoms will go

away. “This is a mistake that’s being endlessly repeated,” said Pilcher. He happened to be working in an urgent care center when a woman came in with these symptoms, and he was astute enough – and asked the right questions – to suspect the patient was newly infected with HIV. She was. And then Pilcher spotted another case, and he began to wonder whether there was a better way to uncover more cases of acute infections in the state.

To determine HIV infection, health care workers test a person’s blood. Most common screening tests for HIV look for antibodies that the immune system makes to fight viruses, rather than looking for the virus itself. Research indicates that the body makes relatively few HIV antibodies in the first five to six weeks after infection, so antibody screening tests during those first several weeks will be negative even though HIV is highly infectious at that time. It’s only in the third month of infection that the body makes enough HIV antibodies to turn the screening test, known as the enzyme-linked immunoadsorbant assay (ELISA), positive. A more expensive test that looks directly for the RNA genetic code of the virus – instead of the antibody – can find the earliest signs of HIV infection.

Pilcher wanted to catch more acute infections because, as his later research would support, that is a time of high infectiousness. With millions of HIV in the bloodstream, the chances of spreading virus to another person skyrocket. “Fifty percent of the lifetime transmission risk is concentrated in the first two to five months of infection,” he said. Finding acutely infected persons would allow doctors to treat them with antiviral drugs and give public health educators an opportunity to influence the behaviors of the most efficient spreaders. At the time, Peter Leone was looking for primary HIV infection among patients at the Wake County STD Clinic, and Pilcher assisted with that study. They were able to find

few acute cases, though, and the lack of results proved a frustrating, negative experience. Pilcher didn't give up on the idea, though.

“The idea to detect acute HIV wasn't new, and the idea for RNA testing wasn't new,” said Pilcher. Yet he couldn't find anybody who had tried screening for acute HIV infections in routine settings with any regularity. (Recently, researchers at CDC and other states have begun to use a testing protocol called the serologic testing algorithm for recent HIV seroconversion, or STARHS, that can estimate new cases of HIV. STARHS uses a modified antibody test that can detect the earliest output of antibodies, as early as 30 days after infection. It still misses the earliest infections.)

Widespread RNA testing had been discounted for years, said Pilcher, for the simple fact that the acute infection window, which is only about two or three weeks, is so much shorter than the many years a person has antibodies to HIV. “What was missed in that calculation was that people get HIV tested for a reason, and that reason is that a person or physician relates the person's behavior to risk for acquiring HIV,” he said. When people do something to cause them to be anxious enough to get tested for HIV, that should be an obvious signal that they may have recently become infected. “It's sort of a no-brainer.”

So Pilcher proposed a pilot study to look at HIV antibody tests that had come back negative. He wanted to retest blood samples from previous ELISA tests using the RNA test. Leone helped broker a relationship with the state lab, which collects and stores more than 100,000 HIV test samples each year from clinics across the state. For the pilot study, Pilcher screened 8,155 samples that had been antibody-negative. He first tested each blood sample using ELISA. Then he used RNA polymerase chain reaction (PCR), a process that makes multiple copies of the genetic code of a virus. This allowed him to measure the amounts of a

particular enzyme, reverse transcriptase, that HIV uses when it makes new virus, a process called replication. Sure enough, five samples turned out positive for HIV genetic code (though one later turned out to be a false positive, meaning the person really was HIV-free).

“It was huge,” said Pilcher. He’d anticipated that the screening would find some acute cases, and when the first pools turned positive, he quickly got on the phone to share the news with his collaborators. (Soon after, the state investigators contacted each of the newly infected individuals with their updated test results.)

The beauty of their testing protocol was that it took just 147 tests to screen all 8,155 samples. By first dividing the samples into master pools of 90 specimens each, and then further dividing whichever pool indicated it included a positive specimen, the team had a cost-effective way to screen thousands of specimens. Pilcher and the team published the results in *JAMA* in 2002, and expanded their pilot program into the state’s Screening and Tracing Active Transmission, the program that looks for acutely infected individuals.

CDC estimates that nearly 50 percent of adults in North Carolina have been tested for HIV at least once. In its first year, the STAT program screened 109,250 blood samples of people who were at-risk for acquiring HIV infection. The first step, using the ELISA, found 583 new positive cases. This was the routine antibody testing that the state lab had been doing since 1987, and so these 583 cases weren’t surprising. But the second step, using the new RNA-PCR test, found 23 acute HIV cases. These were new cases, and while they represented a net gain of just under four percent of the total yield of positive samples in the screening, Pilcher found the results satisfying, because those cases would otherwise have been missed by the traditional screening. Another CDC estimate suggests that 25 percent of Americans infected with HIV don’t know it, and a 2002 abstract from the XIV International



AIDS Conference even reported that three-fourths of HIV-positive young MSM in six U.S. cities were unaware they were infected. Pilcher's new testing protocol was finding some of those unaware people here in North Carolina.

“What they've put together will fundamentally change the way HIV is diagnosed in the U.S.,” Joseph Eron told me just after he sat down from his morning bicycle commute to his office, where he shares the church choir loft with Pilcher. Eron is the principal investigator for the UNC AIDS Clinical Trials Unit, which, among other activities, helped determine that a new type of drug called fusion inhibitors could be added to the range of antiretroviral therapies to treat HIV. Finding infected people during the acute stage will have a huge impact on individual health, Eron said.

Some virologists suggest that antiretroviral therapies, in addition to blocking HIV from replicating, can boost the immune system's defenses against HIV and help it wipe out as much of the virus out as possible. It's possible that by treating a person with acute HIV infection with antiretroviral therapies, and keeping that person on those drugs forever, that fewer CD4+ cells are destroyed, giving the person longer to fight off the virus. Eron hastened to tell me that this theory has yet to be demonstrated, though he tends to believe in research that suggests early treatment does provide a benefit. He said the conservative approach to treating one of the acute cases would be to put the person on the therapies indefinitely. “That patient has an opportunity that a chronically infected person never did.”

Finding acute cases of HIV also has important implications for the epidemic, explained many of the other experts I spoke with.

The STAT program provides the first real opportunity at real-time surveillance of the spread of HIV, Pia MacDonald told me. MacDonald is director of the N.C. Center for Public

Health Preparedness and an epidemiologist who assisted in the college outbreak investigation. She'd been a field officer with the CDC's Epidemic Investigation Service and served with North Carolina's general communicable diseases branch. Knowing a person had become infected just weeks before, she explained, allows public health workers to get to that person and learn as much as possible about how that person became infected.

That leads to more reliable information. In epidemiology, recall bias is an important consideration when asking people to remember what they did or didn't do many years in the past. AIDS experts say this is especially important in trying to stop the spread of HIV, because patients can't always recall names of past sexual partners, and when they do, those partners have often moved. Why the STAT effort is so important, Eron said, is that when individuals are tested for HIV and told that they are positive, it's likely they were infected five or six years back. Finding the acute cases – those persons only recently infected – gives public health officials better opportunities to track down more partners.

“The college outbreak is so illustrative of that,” Eron said. The first two cases of acute HIV helped to unravel the larger outbreak. But the UNC-CH researchers might never have connected those first two cases to the larger outbreak. It was Leone's dual roles, as UNC-CH researcher and medical director for the HIV/STD branch of the state health department, that allowed Hightow access to the state's extensive collection of files about individual patients. Indeed, ten years earlier, Leone had seen four college acute cases, and van der Horst another two, but Leone hadn't started at the state yet and they couldn't compare their information to the larger state numbers.

Since 1989, North Carolina has had a partner counseling and referral program. When a person tests positive for HIV, the clinic or testing laboratory is required to report that

person's name to the state health department. Within days of receiving that report, the state sends out a disease intervention specialist (DIS), who first verifies the test's result and then interviews the person about the circumstances that led to infection. These interviews are voluntary, yet in 2001 86 percent of the infected individuals agreed to be interviewed, and they named 1,532 of their needle-sharing or sexual partners. The intervention specialists tracked down most of those partners, and of them, 108 were HIV positive after being tested. As they interview people, the intervention specialists follow a standard questionnaire, but they also take notes on seemingly extraneous details. It's these notes that proved invaluable to Hightow when she was first looking for college cases. The DIS questionnaire, she said, didn't include specific questions about a person's college enrollment or fraternization with college students. Since the discovery of the college outbreak, though, the questionnaire has been expanded to include questions about college status as well as whether or not the person has had contact with college students.

Put together, the STAT program and the partner notification program became a one-two punch against HIV in North Carolina. Pilcher credited Evelyn Foust, head of the state HIV/STD Prevention and Care Branch, for her enthusiasm about "about doing something so completely new." I met Foust in her Raleigh offices, and her support for the STAT program seesawed with a passionate complaint that the state wasn't getting the federal attention it deserved.

Foust calls herself and her colleague Judy Owen-O'Dowd the "founding mothers" of the state's HIV prevention program. The two started working on AIDS prevention in 1986, and since then, said Foust, they'd fielded frequent requests for state health department funds to be directed at one HIV research project or another. Foust was intrigued by what Pilcher

and Leone proposed to do with acute HIV testing, and kept thinking about how the opportunity to inform people about their HIV status as early as three to six weeks post-infection created a new paradigm for public health. “The possibilities were endless. We could finally see and document the prevention of HIV.” The ability to respond quicker to new infections, and possibly stop even more infections, excited her staff.

“We’re doing groundbreaking public health work with Chris [Pilcher] and Peter [Leone],” said Foust, proud that North Carolina was the first government to be testing large numbers of blood samples for acute infection. Pilcher told me he’d heard through the grapevine that health departments in San Francisco, Seattle, New York State, Johannesburg and Brazil were beginning pilot STAT programs of their own, and Thena Durham confirmed the CDC was planning to fund acute-screening pilot programs in seven or eight other cities or states across the country. The fact that North Carolina, as a rural Southern state, was showing success with the STAT program but still meeting foot-dragging from CDC grant makers, Foust said, revealed to her a bias about where important discoveries are meant to emerge. New York City had announced a few days before that there were 75,000 HIV-positive individuals in that metropolis, and Foust was bothered by the publicity that that number was getting. Quoting Albert Camus, she asked how many bodies the nation needed to see coming out of North Carolina in order to focus on the state. She complained that the N.C. college outbreak – and the STAT program that pinpointed the outbreak – was getting only a subdued professional nod when the nation should have been excited about a dramatic and successful new way to stem the tide of HIV infections. “I think a trumpet would have been blown if this had been in a big city somewhere,” she said.

Foust had been a co-chair of the Southern State AIDS/STD Directors Work Group that had written a call to action called the “Southern States Manifesto,” and she was angry that one region of the country was getting less care. “I’ve been told, ‘You know, Evelyn, the South has always had problems.’ I get very mad about this. It says there’s not that national commitment to providing care for all persons,” she said. “I intend to scream about this until the day I retire.”

Foust wanted more funding, naturally, and complained that while the state was “on fire here,” the federal government was keeping the state’s HIV prevention allocation at the same level as the year before. Funding for the STAT program is to run out in December 2004; Foust wanted \$403,000 more to continue the acute testing for one more year, but that request had been declined by early March 2004. Similarly, Foust submitted a request to state lawmakers for an extra \$12.1 million dollars on top of the \$8.3 million they already contributed to the AIDS Drug Assistance Program. (In fiscal year 2003, Congress gave N.C. an additional \$12.7 million.) North Carolina’s ADAP program provides drugs, insurance and care to 3,600 individuals, but has close to 500 HIV-positive people waiting to join the program. Foust’s request would enroll those 500 as well as change the eligibility requirement to 200 percent of the federal poverty line from the current 125 percent.

In North Carolina at the end of 2003, Owen-O’Dowd informed me as I left my meeting with her and Foust, there were 16,894 individuals living with HIV infection or AIDS. “And that’s just the people we know about,” said Foust. Her great despair, she told me, is that her five-year-old daughter would grow up to be sexually active and HIV would still be around to threaten her. “That infuriates me,” she said.

I

n February, author E. Lynn Harris visited Duke University to read from his memoirs that chronicle his struggles with his sexual identity. Harris's 1991 novel about black male sexuality, *Invisible Life*, included one of the first descriptions of what would become known as "living on the down low." (Men having surreptitious sex with other men and then going to home to their wives or girlfriends certainly isn't new. In his 1994 memoir, *My Own Country*, physician-author Abraham Verghese wrote about how he treated his first AIDS patients and learned of their trysts at Tennessee truck stops.)

"Who in their right mind would choose to be black and gay in a world that has problems with both?" Harris asked, to murmurs of assent. "Why are we having this [college] HIV crisis? Because these young men are afraid to say what's so. They're just listening to their rain dreams." Rain dreams, as Harris explained it, are society's hopes and desires for a person – hypermasculinity for African-American men – rather than that person's true, authentic desires. Those he called his snow dreams. "It took for me waking up from a suicide attempt," he recalled. He spent time "with himself, by himself," and emerged an energized writer and openly gay man who would win numerous awards for his novels and memoirs.

In his introduction of Harris, Duke senior Dale Johnson described himself to the audience as an African-American gay male, and said Harris had been an inspiring influence. When I told Johnson later that he'd said that so matter-of-factly, he admitted that it had been his first public announcement of his sexual identity, and he was glad he'd come across so confidently. Later, over gelato and biscotti at a Durham cafe, Johnson explained that while he was open about his sexuality at school, his family in Charlotte didn't know he was gay. (At his request, I've changed his name.) Part of his mother's homophobia, he said, included misconceptions about HIV. "My mom says to me, 'It's a white disease, not a black disease.'

To most African Americans, the face of AIDS is white and gay.” As he learned to be true to his real identity, he felt like he was a pioneer establishing himself on the frontier land.

The college outbreak, he told me, had a lot to do with the fact that fewer than half of African-American high school students go to college, according to figures from the American Council on Education. Citing W.E.B. Dubois’s *The Talented Tenth*, Johnson said the perception in the black community today was that African-American college students are too smart to have AIDS. “One of my friends has AIDS, and he’s so smart,” he said. His friend confided to Johnson that he was HIV-positive at a time when Johnson was becoming sexually active on trips to Europe and New York City. “It hit me hard. We were talking about our lives one day, and he told me he had something important to say. He knew what my reaction would be – I’d burst into tears. But I didn’t. I dried right up. I didn’t want to [burden him]. It’s the first time I began to think about someone else.”

Later, Johnson’s friend urged him to get tested for HIV. “The fear of getting tested is a bitch,” he said. But he did get the courage to go, accompanied by his friend. At the Healthy Devil, Duke’s student health service, he was turned away because he didn’t have an appointment, and he still hadn’t been tested when I spoke with him. Jean Hanson, assistant director of the Duke student health service, explained that it wasn’t practical to have a nurse waiting at all times to test walk-ins, but she did concede that the Healthy Devil needed to advertise its testing more widely. The Healthy Devil offers confidential testing, with results disclosed with written permission, as well as testing that is anonymous unless the test result is positive. State law requires a positive result to be reported, along with the person’s name, to the state health department. Hanson said that recently she’d been seeing more men than women come for testing, often at the urging of their new girlfriends. (Many of the students

getting tested for HIV do so as a requirement for study abroad programs, as well.) Hanson, who has been a nurse at Duke since 1982, said the university's testing had produced only three positive results since 1982 – until a fourth student tested positive last fall. In an e-mail exchange, Hightow told me this Duke student was not tallied in the 84 college positives. Lisa Fitzpatrick stated that she was sure the numbers weren't accurate, since data on college students were incomplete, and Peter Leone had said earlier that out-of-state students at private universities often get tested with their family physicians.

At Leone's suggestion, the Healthy Devil has broadened its testing net, making it routine to test any student who requests a test for another sexually transmitted infection.

For the CDC investigation, Fitzpatrick interviewed 50 students at historically black colleges and universities, both men and women, to ask them about HIV prevention messages and campus testing policies. "Students told us, 'If you want us to test on campus, you have to do three things: you have to make it completely confidential, you have to make it free, and you have to integrate it so that it's a routine service at the medical clinic.'" She said that many colleges, if they do offer confidential testing, offer that only during a four-hour window. "Which means, if someone is approaching a clinic at that time, someone [else] might deduce that they're going for an HIV test. That was of grave concern to them. When we first asked if they would get an HIV test on campus, there was a resounding 'no.'" Her recommendation to campus health centers is to "listen to the students if this is what it will take to get them to have an interest in testing on campus."

State officials were unable to provide neither reported numbers nor estimates of how many N.C. college students get tested for HIV. Fitzpatrick found that about 70 percent of the men in her study had previously been tested for HIV. She wanted to know why these men



were getting tested and still exhibiting risky sexual behaviors. “Are they presenting for HIV testing because they feel they’re at risk or are they going because someone has asked them to, and then once they find out they’re HIV-negative, are they continuing to engage in behaviors because they think, ‘Oh, I can continue to do the same things I was doing because I’m HIV-negative.’ Is that a missed opportunity for us to impart HIV prevention messages to them?”

As far back as 1988, recalled Hanson, public health officials had been warning that students were a prime target for HIV. She suggested that HIV was finally touring campuses because the sexual behaviors of students at Duke and other colleges had changed, with more of them partaking in a “hook-up culture” in which sex precedes a steady relationship. And she said, the fact that students now come for HIV and STD testing between relationships suggests they’re not practicing safe sex when they’re in relationships. In February 2004, Duke Student Health Director Dr. Bill Christmas told the *Duke Chronicle* that “students are now beginning to use testing as a way of prevention rather than safer sex practices.” Johnson concurred. “People get that clean bill of health and they think, ‘that means what I was doing wasn’t bad.’” That’s what happened with his friend, he said. “He rolled the dice, but sometimes education can equate to ignorance.” He meant that the knowledge of a negative test result can be liberating yet lead to risky behavior. His friend, he says, knew about risky behaviors and safe sex – he worked at an AIDS research clinic. “We all make stupid decisions sometimes, but that doesn’t mean we’re stupid.”

**I**n Greensboro, 75 percent of those with HIV and AIDS see doctors at Moses Cone Hospital, where physician Timothy Lane works. His practice cares for more than 800

patients, and he and his colleagues see 125 new patients each year. “HIV care is complicated,” he said. “If you don’t do it daily, it’s impossible to do it knowledgeably.” Over the years, Lane has been invited to area colleges to speak about the AIDS epidemic. The first colleges to invite him, in the early 1980s, he said, supported gay, lesbian, bisexual and transgender organizations on campus. The last school to invite him to speak still has no GLBT organization, and that school has one of largest clusters of cases from the college outbreak, according to investigation documents I received. Lane suggested that school was a perfect example of the danger of stigma. (Leone and the others have refused to name the 37 schools involved in the outbreak for fear of stoking homophobia on those campuses. An incident at Atlanta’s Morehouse College in 2002, in which a male student was violently assaulted in a gay-bashing crime, has educators understandably nervous. The documents I received did indicate which schools were involved, but I’ve chosen to also hold back the names, since I was unable to confirm with administrators at every school.)

Lane is familiar with acute HIV infection. Indeed, he had come across another example of timing being everything in the testing of HIV when he helped investigate how three organ recipients contracted HIV in August 1986. A 30-year-old man who’d smashed his car into the concrete pillar of a railroad underpass and flew out his car window was brought to the Moses Cone Hospital emergency department, where doctors struggled to control the massive bleeding from the man’s head injuries and neck cuts. Through the 12-hour surgery, doctors pumped 56 units of blood, plasma and platelet infusions into the patient. He stayed in a coma and died a few days later.

Because the emergency surgery had been so bloody and messy, one of the doctors tested the man’s blood for HIV, using the antibody test on a sample of blood that was taken

toward the end of the surgery – after the transfusions. The test came back negative. When the man died, his family consented to donate his organs (kidneys, heart, liver), which were quickly sent out and put into three patients in other parts of the country.

Donated organs that are sent to waiting patients are accompanied by a blood specimen. This allows transplant surgeons to test for blood type compatibility. The hospitals that received the crash victim's organs also tested for HIV, but organ transplantation is a race against the clock, and the organs had to go into the waiting patients before the HIV antibody test results could come back. By then, one of the hospital labs had found the blood to HIV-positive. Lane, back in Greensboro, tested a sample of blood taken from the man when he first came into the emergency department. Sure enough, that sample was positive for HIV antibodies, and all four organ recipients became HIV positive.

“This is the only case, to my knowledge, of a falsely negative serologic test caused by dilution of multiple transfusions,” Lane told the 25<sup>th</sup> reunion of his Cornell University Medical College class. All the extra blood the man had received during the emergency surgery had replaced so much of his own blood that there weren't enough HIV antibodies to trip the test.

In the first years of the AIDS epidemic, the blood banking industry became infamous for its recalcitrant refusal to accept responsibility for testing blood for HIV. Since 1999, says the American Association of Blood Banks, blood banks have used the RNA test to screen for blood for acute HIV using a protocol similar to what Pilcher designed for North Carolina's STAT program. “Why is the entire U.S. blood supply protected by this system?” UNC-CH's Joe Eron asked. “Because the thought of Grandma Smith getting HIV from a transfusion is intolerable.” He wondered why this wasn't so for all HIV testing.

Traditional testing is missing HIV-infected people, Eron said. “What will sell this program to the public is the concept that in a clinic testing for antibodies, five out of a hundred people who have HIV leave thinking they’re negative. Once people start thinking about that, perhaps a parent thinking about a daughter in college, then people will care.”

**I**n the months I researched this story, I heard variations on a theme about the possible solutions for stemming this outbreak. “Sexual health education needs to be universal. Everyone needs to know the risks of STDs,” said the Whitman-Walker Clinic’s A. Cornelius Baker, who cited recent figures released at the 2004 National STD Prevention Conference that estimates people under 25 account for nearly half of the 19 million STD infections in the United States each year. “Clearly we have a population that isn’t educated,” he said.

“The major problem in N.C. is that our school boards are terrified of a minority of parents who don’t want any discussion of sexuality in the schoolroom,” Charlie van der Horst said on the WUNC-FM public affairs radio program State of Things in February 2004. (He and Leone were interviewed about HIV in North Carolina and Africa in a show that tied into a campus-wide HIV awareness series I had organized at UNC-CH.) “People have their heads in the sand here. As long as we have our heads in the sand, HIV will prey on our ignorance. And when we have ignorant school boards, this [increase in HIV] will happen.” He explained that four years earlier, he had identified two HIV-positive college students. His letter to the then-president of that university, proposing a race-conscious HIV awareness program, was flatly refused – “despite the fact that I knew that one percent of his students were HIV-positive, which is an extraordinary rate.”

Leone agreed with van der Horst about sex education in schools and suggested the approach to that was wholly different from other safety messages children receive. “We have driver education courses in school. We don’t say ‘Don’t talk about seat belts because we might encourage kids to drive fast. We’ll let them figure it out on their own once they’re in a car.’ We go so far as to tell them how they should put in on and when they should put it on.”

“We need to destigmatize sexuality no matter what it’s for,” said Baker. He told me what others had said – that in the African-American community, condom use is seen as being distrustful of a partner or, worse, self-implicating. “Using a condom should be a sign of being a healthy and well-educated individual,” he said.

I asked Leone what could be done. “Maybe we need to change our approach. The problem we’ve gotten into is we’re always looking backwards rather than looking forwards. So you’re always describing what’s already happened as opposed to where is it moving and where do we need to go. And that may be a different set of questions we should be asking.”

Leone said a lack of social dialogue that could help young people understand their sexual identities instead pushes those students into high-risk behavior as a way to figure out who they are.

While most of the cases are not from the historically black colleges and universities, Leone said, the impact on those campuses is more significant. Those colleges historically have nurtured black leaders, he said, and they had gathered together to discuss the college outbreak. “It’s been really remarkable and encouraging to see movement on their part to be willing to talk about it. I haven’t seen any other university system folks do that.” The Stomp Out HIV/STD conference reflected the interest among those colleges. That conference was organized by Phyllis Gray in the state HIV/STD Prevention and Care Branch as part of the

Commit to Prevent program, an effort to promote more dialogue about sexually transmitted infections on the HBCU campuses. Thena Durham, deputy director of policy for HIV at the CDC, was in attendance at that conference. “The most memorable part was seeing all those young people in the room. They were interested and prepared to go back to their campuses with the message,” she told me. “It reminded me very much of my youth when the issue was civil rights. We’d gather, pump each other up and then go out to make a difference.” Peer education hadn’t gotten the attention it deserved, she said. “Young people listen to each other. That’s a known intervention that works.”

Durham returned to the CDC and helped arrange funding for North Carolina to continue its efforts among the African-American college students. Leone told me the CDC had promised \$2.25 million, to fund three years of the state’s Black Male Health Initiative, as well as Project Commit to Prevent and the CDC’s own Popular Opinion Leader program, which enlists key community leaders to spread the word about HIV prevention. And, Leone said, the governor’s office was interested in funding another year of the acute HIV testing program.

In the months he’d been publicly speaking about the college HIV outbreak, Leone had heard from naysayers. One day, he received an e-mail message from a man who identified himself as a voter and asked, “Why should we spend any federal money on our so-called best and brightest who aren’t bright enough to figure out how not to get infected?” Leone promised to respond to the message. “First of all, even if you don’t care, it’s going to cost the society and you money. Every case of HIV costs around \$250,000 over the course of a lifetime for that person’s medical management. You should be concerned about it just from

the impact on your pocket book. If you say you don't want to pay for prevention, you're going to pay for it anyway."

By the end of March 2004, there was a buzz in the African-American community and extensive media coverage. "Oprah is apparently interested in this story," Leone said, and recognition was finally coming from state and federal officials. Leone was excited about the prospects. "All of this is a watershed moment, an opportunity to recast the die in the African-American community for how HIV is discussed."

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