

Scholar, Witness or Activist: The Lessons and Dilemmas of an AIDS Research Agenda

Patricia Siplon, Ph.D.

Assistant Professor of Political Science

Wilkes University



Fifth Annual Final Word Lecture

Faculty Recognition Day

Wilkes University

May 11, 1998

**Scholar, Witness or Activist:
The Lessons and Dilemmas of an AIDS Research Agenda**

The study of AIDS, as a disease, a social problem, or in my case, as a political phenomenon, is not tidy. Learning about AIDS requires invasion of the most private spheres of peoples' lives, it involves watching people at their most vulnerable, and often it takes becoming closely involved with people whose lives and circumstances are far away from the researcher's own comfort zone. As the title of my talk suggests, I have found myself taking on a variety of roles in order to gather the information I sought, and, sometimes, *because of* the information I had gathered. Roughly speaking, these roles can be characterized with respect to the distance of the researcher from the subject matter. As a scholar I endeavored, particularly in the early stages of my research, to hold myself apart from what I saw and to weigh it against the work of other researchers. However, as time moved on I found myself increasingly in the two other roles, roles that I have characterized here as witness and activist. This move to lessen the distance between myself and the subjects of my research came from both practical and personal motivations. As a practical matter, like many other social scientists, I quickly discovered that I had far greater access to information, in the form of written documents, interviews and observation opportunities, as an insider. From a personal view, I found myself wanting to contribute what I could to help with the problems unfolding all around me.

What I hope to share with you in this Final Word talk is twofold. First, I would like to tell you about some of the insights and information I gained from my work in each of these three areas. And second, I would like to offer an answer to an eternal question, centered around the idea of objectivity, that plagues all of us as researchers. Is there a magic line that is not to be crossed, and, if so, where is it?

In the early stages of my work as a scholar of the political movements surrounding the advent of AIDS, my first concern was not with the issue of objectivity. Rather, I found myself exploring many of the same questions as other scholars who focused on the human side of the emerging pandemic. A puzzle to many of us was why AIDS had been such a strong mobilizing force. An additional question that intrigued me as a political scientist centered around the phenomenal success of this AIDS movement once mobilized: the people it mobilized seemed to have been remarkably successful both in having their policy demands met and in incorporating themselves at the decision making levels where future policies would be formulated. These successes seemed all the more amazing given the association of the epidemic in the minds of Americans with groups of people who were seen as, at best, marginal to the American mainstream — the diseased (in the

Wilkes University Press
Wilkes-Barre PA
1998

case of hemophiliacs), the unwelcome immigrants (in the case of Haitians), and most especially, the morally unacceptable (in the case of gay men and injection drug users).

The explanation for this paradox of unprecedented success for unlikely actors has spawned a whole literature on the subject across a variety of disciplines. Early books on the subject, beginning with Randy Shilts' (1987) unequalled classic, *And the Band Played On*, focused on the manifold obstacles facing early activists and government officials attempting to deal with the impending crisis. Books with titles like *Good Intentions* (Nussbaum 1990), *AIDS in the Mind of America* (Altman 1986), and *The AIDS Disaster* (Perrow and Guillen 1990) represented further impressions from a journalist, a political scientist, and two sociologists, respectively, on the difficulties of activists in waging their fight against the disease and a government they perceived as indifferent. As the tide began to turn with new medications being released in unprecedented time frames, clinical trials being redesigned at the behest of activists, and a variety of other activist-initiated demands being met, the literature began to reflect this as well in books with titles like *Against the Odds* (Arno and Feiden 1992).

My own scholarly impressions and conclusions have filled a few reams of paper at this point, but for brevity's sake I would like to mention three lessons that I have drawn from my study of AIDS and the people it has mobilized (and in some cases, failed to mobilize). Here they are:

Lesson Number One: The key to successful mobilization around an issue like a disease lies in the decision of a community to "own" the issue.

What do I mean when I use the term "own." I do not view ownership in the sense of merely being associated with a given issue. Rather, to own the issue is to have legitimate claim or title to it, and by extension, to claim the right to construct the ways in which it will be defined and managed. This lesson may seem self-evident hindsight. But I will offer the assertion here that, until AIDS, it was exceedingly rare, if not unprecedented for a disease-affected group to "own" the disease in the sense I am describing here, particularly when the disease was, like AIDS, transmitted through morally unacceptable practices. Think of the interest groups composed of people infected and affected by syphilis, gonorrhea, hepatitis or cirrhosis of the liver. There are none. That is because people with these diseases do not want to be associated with them, let alone "own" them.

But what about diseases that the afflicted *are* associated with, and that carry a minimized stigma? There are many diseases in this category that have served as a focal point for interest mobilization: polio, cancer, muscular dystrophy and a great many more. But the key difference between mobilization around these diseases as compared to mobilization around AIDS is that the afflicted in these instances are presented as *victims* and victims are helpless people. They are associated with their diseases, they may draw support, financial and even political, from the average

well-wisher, but the afflicted do not seek, nor are they given power to define their experience, nor to dictate the policy solutions posed by these diseases. This power is reserved to the government bureaucrats and especially to the medical profession on whom these people rely.

What is different in the case of AIDS is that one group within the early-identified at-risk categories, gay men, together with the larger gay and lesbian community consciously viewed the ownership of AIDS by government and health professionals as a threat and challenged that ownership. The manifestations of that challenge have taken many forms: enormously expedited FDA approval of experimental drugs (because AIDS activists decided to define for themselves what was a "reasonable" period to wait); successful demands to lower the costs of those same drugs (again because activists had their own view of a "reasonable" price); changes in clinical trials to give more power and information to the people with AIDS who volunteered for them; successful demands to make prevention and educational materials oriented toward the groups (including the gay community) that would be receiving them even in the face of offended community leaders; and a redefinition of the health provider-patient relationship that acknowledged the patient as the final arbiter of medical decisions. These victories have benefited all people with AIDS, but most of the original demands came from activists in the gay community. This brings us to:

Lesson Number Two: Having a disease does not automatically make you part of a community and not having it does not necessarily exclude you from that community.

Most Americans associate AIDS with the gay community. Most scholars assume this association is a logical extension of the fact that AIDS was first recognized in gay men, and that gay men have cumulatively been the demographic group most severely affected by AIDS. I find this explanation unsatisfying for several reasons. First, it does nothing to explain why lesbians, a statistically low-risk populations have been so active in the AIDS movement, and second, it fails to explain why AIDS was owned by any community at all, a point discussed in Lesson Number One. Furthermore, if we are looking at proportions of the population affected, between the years of 1981 and 1985 approximately half of all hemophiliacs in the United States were infected, easily the highest infection rate of any of the four groups identified by the Centers for Disease Control as at-risk populations.

The official pronouncement about the four at-risk groups was made by the CDC on March 4, 1983. At that time the CDC recognized what came to be facetiously called the AIDS 4-H Club: homosexual men who had multiple sexual partners, heroin users who injected intravenously, Haitians who had recently immigrated to the United States, and hemophiliacs. The responses of these groups, and of the communities they belonged to, could not have been more different.

Of these the Haitian community response was perhaps most unequivocal.

Already in a tenuous position with many members of the community living in the United States either conditionally or illegally, the Haitian community emphatically did not want any association with this new and dreaded disease. The community did mobilize, but with the express purpose of *disassociation* from AIDS. Its goals were to be removed from the official CDC typology mentioned above, and to be taken off the FDA list of people barred from donating blood. In April 1985 the CDC took Haitians off their list, but it was not until a massive series of demonstrations along the east coast, culminating in a New York City action supported by Mayor David Dinkins and the Reverend Jesse Jackson, that the FDA rescinded its ban in 1990 (Farmer 1992, 219-220).

Predictably, heroin users did not organize. However, the communities living around them did and, like Haitians, they were not interested in owning this new problem. Although injection drug use is a widespread phenomenon that cuts across social and demographic categories, it is most strongly associated with our nation's inner cities. And the last thing that community leaders in those inner cities (the majority of whom are clergy or closely connected to religious organizations) want is to squander their resources on the policy solution that was first presented to them to help control the spread of HIV. That solution was needle exchange. Although needle exchange programs may take different forms, they all operate with the same goal: to stop the spread of HIV by providing uncontaminated needles to the drug injecting population. Community leaders saw the policy as a cheap substitute for the real solution, drug treatment for anyone who wanted it. Further, they saw the issue as racially tinged, suggesting that those who tried to push this issue either did not understand or did not care about what the community itself saw as its chief problems. One New York City African American City Council member referred to it as "Genocide; pure and simple." (Joseph 1992, 191).

On the surface, perhaps the most puzzling case is that of hemophiliacs. Unlike the two groups just discussed, they already had a single and effective lobbying voice for hemophilia issues on the job in Washington, DC in the form of the National Hemophilia Federation. Although the consequences of their infections were just as deadly as with the other three groups, they carried less stigma. Even politicians normally opposed to AIDS funding could be counted on to argue that hemophiliacs, as "innocent victims" were entitled to government concern. Yet hemophiliacs ironically fell victim to their own earlier successes, in that they followed a model of interest organizing that AIDS activism and the circumstances of their own infections, had made obsolete.

In short, the problem for hemophiliacs is that their own interest group had won its successes in earlier decades by forming alliances with the pharmaceutical industries that provided the clotting factor products that hemophiliacs so desperately needed. In the seventies and eighties the NHF had successfully lobbied for government-subsidized research and hemophilia treatment centers. This benefited both hemophiliacs and the pharmaceutical industry at the time, but it also cemented

a very tight bond between the NHF and the pharmaceutical industry. During the early years of the AIDS epidemic hemophiliacs and their treatment providers followed exactly the opposite path that AIDS activism was blazing. While AIDS activists were demanding accountability from the pharmaceutical industry in terms of pricing, drug product availability and choice in treatment options, hemophiliacs were instructed by the NHF (which was instructed by doctors connected with *both* NHF and the pharmaceutical industry) to continue passively taking the HIV infected factor products.¹ In short, hemophiliacs did not organize because they did not know they needed to. When they understood what happened to them later many were enraged and did in fact join in the activist movement, but by that time its terms and identity had already been defined.

The gay community owned the epidemic in part by default. Gay men were the first to be diagnosed with the disease, and they were the only community that did not reject ownership outright in the beginning. But ownership was not a passive issue. One of the first questions that confronted the gay community was the issue of preventing the spread of the virus. The gay community, lesbians included, saw itself with two options: either take an active role in figuring out how to stop transmission or have the government do it if, when and how it saw fit. The gay community correctly assumed that government-produced information during the Reagan administration would not be written in a gay-neutral, let alone gay-positive tone, and that community institutions like the bath houses where many gay men went to have sexual encounters would not be considered worthy of preservation outside of the community. Thus, the gay community took these issues on to preserve the institutions and attitudes in a community that had already been built. As the activist movement continued its work and took on other issues, particularly in the area of patient rights and treatment, the importance of having lesbian activists became apparent. Many of the lesbians who were active in ACT-UP and other activist groups were veterans of the women's health movement of the seventies. They reintroduced many of the self-empowerment concepts they had promoted before, and these became a source of many of the activists' successful demands.

Lesson Number Three: Lesson Numbers One and Two are in danger of being lost in the years ahead.

Despite, and in part, because of, the movement's success, the nature and demographics of the epidemic are changing. Even during the height of the epidemic the proportion of gay men with AIDS was falling while the incidence among other

1. The best example of the misinformation that was given to hemophiliacs comes from the National Hemophilia Foundation's own newsletters, Medical Bulletins and Chapter Advisories. See for example, July 14, 1982 Hemophilia Newsnotes, Medical Bulletin #10/Chapter Advisory #13 (January 24, 1984), Chapter Advisory #14 (February 3, 1984) and Medical Bulletin #11 (January 30, 1984).

groups was climbing. In 1981 100% of all AIDS cases reported to the CDC occurred in homosexual men, compared to 56% in 1991, and 46% in 1993 (Stine 1995, 194). By June 1997, the proportion of AIDS cases reported for the previous year where men having sex with men was listed as the risk category had dropped to 38 percent of new cases. (CDC 1997, 8). As elsewhere in the world AIDS is increasingly becoming a disease of the poor, of racial minorities, and of high levels of association with drug abuse. The advent of a host of treatment options which in combination can bring viral loads down to near undetectable levels are a godsend, but only to those lucky enough to have generous health insurance. It is becoming harder and harder for AIDS service organizations to raise money, and burned-out volunteers are getting harder to replace.

AIDS will cease to be viewed as a pressing problem *not* because it has been solved. There is no vaccine, there is no cure and there are more HIV-infected people now than ever before. AIDS will cease to be a pressing problem because people will stop pressing the issue. As AIDS moves increasingly into communities of color besieged by other problems the solutions that worked when AIDS was owned primarily by the gay community will become less and less relevant. AIDS activism was a successful phenomenon in the 1980s and early 1990s precisely because the gay community first decided to own the issue and then chose to press for policy solutions that made sense within the community. The same process needs to happen again, but in a community with many more problems, and far less inclination to take on a new one. As a scholar I can only hope that the lessons this tragic disease have afforded us will not need to be relearned at great emotional and physical expense.

This discussion, however interesting on a theoretical level, fails to convey so much of what I learned in my studies. Political scientist Richard Fenno offered some legendary advice to his junior colleagues in the field when he suggested that the path to knowledge is through "soaking and poking". (Fenno 1978, 250) His point was that it is through this type of experience that research questions are derived and foci sharpened. What I would add is that, at least in a field like AIDS, it is through experience at this intimate one-on-one level, what I would describe as "Witnessing", that a researcher comes to understand the intensity of the experiences of his or her subjects. In an effort to convey some of that intensity to this audience I would like to briefly describe the true experiences of two of the people I met during my research.²

The first of these people, a woman I'll call May, was one of the first women with AIDS that I got to know during my nine years of association with AIDS organizations and activism. I had joined a program that matched volunteers (like me) with people who could use an extra pair of hands for one afternoon a week

(like May). My vision of my new volunteer role was that I would wash dishes, do laundry, and run errands during my hours of volunteering. What I learned was that these tasks take on profoundly different levels of difficulty and priority for someone as multiply afflicted as May. This is because, although May had AIDS, her disease was one of a multiplicity of problems, all competing for attention at any given time. May lived in Roxbury, a Boston inner city neighborhood so crime ridden that I could only come visit her during daylight hours: the agency that coordinated my volunteer service forbade me to go at night. The neighborhood was so bad that taxis usually refused to drive on her street to pick May up for doctor's appointments, and the mailman routinely dumped his mailbag outside the building rather than enter the premises and individually deliver the mail in cubicles that had broken locks anyway. While this would be a nuisance anywhere, it was a serious problem for May because her disability checks could not be reliably expected to reach her, and there was no bank in her neighborhood that offered a direct deposit service. My plans to do grocery shopping and laundry were quickly dashed because there were neither supermarkets nor safe laundromats within walking distance or even accessible by public transportation.

The most important service I did for May was to listen. In fact, we developed a ritual where I would come on Thursday afternoons, make her tea, wash her dishes and then sit down for several hours to hear the news of her life. Almost all of it was bad. Despite May's full-blown AIDS, she was not the sickest member of her family nor the neediest. May's father had tertiary syphilis and was displaying both the physical and mental symptoms. May's two daughters both had two children of their own. Neither May nor her daughters had received financial help from the fathers of their children although one of her daughters was still involved in a physically abusive relationship with the father of her children. The other daughter, like May, had a history of drug abuse. In the time that I knew May all of these people came to her with their problems and I never saw any acknowledgment from anyone that they understood that May herself had a fatal disease. I have no way of knowing if May's family was exercising some form of denial about May, but I do know that, even with her illness, May was expected to be the strong one in her family relationships.

May's history with drugs had clearly had an impact on her, positive and negative. When I knew her she was devoutly religious and actively maintaining her recovery in several 12-Step Programs. But she also had behaviors left over from her "junkie days." She could be very emotionally needy, irrational and manipulative. She would sometimes become angry for no reason that I could discern and she would often make plans that she would not carry through or cancel at the last moment. Yet walking in May's footsteps, even in the very limited way that I did, gave me a sense of the intractable obstacles she faced. For May, and for many, if not most, of the people who suffer from AIDS, the question is not what to do about the problem, but where to place it in a seemingly never ending array of societal barriers. May

2. Although these stories are, to the best of my knowledge, factually accurate, I have chosen to change the names of the two people involved to protect their privacy.

had conquered her drug dependency and started down a new path in her life as a community outreach worker when AIDS swept her back into the world she had been trying to escape. I have known many people who wonder why people with AIDS, people with drug dependency problems and people on welfare, all categories that May had fallen into at various times, don't "know better." Seeing the world that May faced daily gave me a far greater understanding of the magnitude of the problems she faced, and the sense of futility and frustration that she sometimes expressed.

May's life experience is so different from most of the audience's that perhaps it is hard to relate to. If that is the case, the next person that I want to talk about should be easier to identify with. Jason was a friend that I happened to know through a part time job that I held. We worked at a very progressive institution, in fact the first of its kind in New England to have an AIDS in the Workplace policy. Jason was young, attractive, and popular with his fellow employees. He had come to Boston in search of a more exciting world than the small town that he had left. Although I did not know it when I first met him, Jason had a history of mental illness, and when he was later hospitalized neither I nor his other friends knew that he had also just been told of his HIV-positive status. We found that out after he had been treated for his mental illness and released. He began experiencing adverse reactions to his medications and then a series of physical illnesses. What then became clear as well is that the parents he left in his small home town also suffered from mental illness and were living in a nursing home. Neither were in a position to help their son, financially, physically, or emotionally. Jason's one brother had cut his family ties years ago and wanted no part in the problems that were unfolding. That left the "progressive" institution where Jason had worked, with its "pro-active" policies and employees. But even progressive institutions have a bottom line, and Jason represented a complicated case. Was he "disabled" because of AIDS, or had he already lost his job because of his mental illness? Seeing a chance to save some money, the institution defined the situation as the latter. Most of the supposedly progressive employees took a similar position. It was one thing to occasionally visit a person with AIDS in the hospital, but when that hospital alternated with a mental ward, and when the visitors found out just how dependent Jason had become on them for human contact they quickly shied away. In a lucky twist of fate I still had many connections to a prominent AIDS organization in the area and was able to help land Jason, who now had no income but disability and was deeply in debt with hospital bills, a place in a model housing program. But it was only a matter of time till Jason was back in the hospital, this time for good. In the end Jason died in a charity hospital. Of the dozens of friends he had before getting sick, only four still regularly visited him, and he died in the night with no one he knew there to say good bye.

Until his illness, Jason's life looked very much like that of most of the people in this room. He was a white middle class young man with many friends and

interests. He had health insurance, a job with benefits, and lots of plans. I am sure that the desertion that Jason experienced from his friends and coworkers was not a conspiracy. No one meant to be mean. But neither did anyone want to be responsible, particularly in a longterm type of situation.

Jason and May are only two of the many people I met who were infected with, or affected by, AIDS. Yet they are for me the face of the epidemic. And in this intensely personal witnessing, I see the holes in the research that I discussed earlier. Yes, the AIDS movement has been successful. But it failed to save these two people and thousands more just like them. Both of them are dead. Both of them, though they came from very different backgrounds, died in publicly financed hospitals, leaving next to nothing in the world. For very different reasons their families failed to support them as they lay dying, their friends deserted them, and the best their communities could do was supply strangers to perform the roles that loved ones normally play. It would take a hard heart to see the AIDS movement's successes and experience in such a personal way its shortcomings and emerged unmoved. Seeing what I saw compelled me to act.

As an AIDS activist I have most frequently used the lessons I have gleaned from my scholarship to work "in the system." While working as an AIDS policy analyst I have helped to organize state and national lobbying campaigns around issues of immigration, testing and confidentiality, and, most recently, needle exchange. It is this last issue that is most controversial by its very nature and by virtue of the form that my work took. I believe in needle exchange in part because of people like May. I know that it is possible for drug addicts to get clean, and I know how hard their lives are when they get clean only to be confronted with the fact that they faced one demon and conquered it in order to die of another. I believe that needle exchange serves as a bridge connecting people who are ready for treatment with immediate access to programs that can help. And, having seen the horrors of AIDS, I believe that no addict, active or otherwise, deserves to die of the disease.

And so, in addition to working with state legislators and grassroots organizations to bring information and witnesses to the statehouse, I have worked with people who do needle exchange itself. It's not easy. In Boston it meant walking a path through the aptly-named Combat Zone from 10 to midnight on Friday nights. If you don't take rejection well, I wouldn't advise it, because there is no quicker way to insult people than to wrongly assume they would be interested in swapping hypodermic needles with you. It also looks funny. The summer I did needle exchange I was on one of a series of teams that had been given a special dispensation by the state to carry otherwise illegal hypodermic syringes as part of a pilot program. A representative from Harvard was also on hand to keep careful records of our "clients." So there we'd be at midnight on a Friday night: a veteran exchanger, two rookies (I was one of them) and a researcher with a clipboard carrying handfuls of condoms, bleach wipes, packaged syringes and a sharps container through Boston's

red light district. It took me a long time to even start to develop an "eye" for potential clients and even longer to be comfortable approaching them. In fact, it's probably a good thing that I never gave up my day job. But I am glad that I did it for two reasons. First, I am happy to have been able to support the dedicated volunteers who are still doing their routes in Boston four years later. They did their work at great personal risk and no gain that I could see, financial or otherwise, because they hoped to save a few peoples' lives. I also saw for myself the complexity of the situation around needle exchange. Politicians don't like the issue because they can't win with it. Few people passionately hope to have a needle exchange program in their neighborhood. Many people passionately object to such programs. And to make it worse, even the proponents can't show that everyone, or even most people, who participate in such a program will eventually give up drugs. But what they can show is that some do, and that there is no increase in drug use just because of the program.

So I've done what I hope is my part. I've walked the streets with needle exchangers, held the hands of dying friends, answered phones, written letters to politicians and bureaucrats, written position papers, helped to organize conferences and legislative hearings, and attended protests. Returning to one of the opening questions of this talk, if there is a line between being an academic and an activist I have almost certainly stepped over, if not actually trampled it until it's unrecognizable. And I think it was the right thing to do.

Many academics feel that an "activist scholar" is a contradiction in terms. One is either an unbiased seeker of truth (scholar) or a prejudiced but pragmatic "doer" (activist). For me, the two have become irretrievably intertwined. Ironically, there is a fourth role that I try to fill and that role is the one that helps me to reconcile the other three. For above all else I see myself as a teacher and in that capacity, as a role model. I tell my students that I have certain hopes for them as they participate in, and eventually, leave, my classroom. I hope they will take ideas and theories seriously, that they will continue to question them after they leave the classroom, and that they will always seek to acquire new and better information. Yet it is equally important to me that they put their knowledge to work, that they stand up when they feel there is a cause worthy of their support, and that they constantly look to use their knowledge to make the world a better place. Given my hopes for them, should I do less than that myself? To act without good information or careful analysis is wasteful at best, dangerous at worst. Yet to dispassionately describe and theorize about a tragedy like the AIDS epidemic in the name of "good science" while doing nothing to stop it is the worst form of irresponsibility. Thus, my final word is that scholarship and activism can and should go hand in hand. Taken together, they are our guarantee that our work is as meaningful as it is intellectually sound.

References

- Altman, Dennis. 1986. *AIDS in the Mind of America: The Social, Political and Psychological Impact of a New Epidemic*. Garden City, NY: Anchor Press/Doubleday.
- Arno, Peter and Karen Feiden. 1992. *Against the Odds: The Story of AIDS Drug Development, Politics and Profit*. New York: Harper Collins.
- Centers for Disease Control and Prevention. "U. S. HIV and AIDS Cases Reported Through June 1997." *HIV/AIDS Surveillance Report*. Midyear Edition. 9 (1).
- Farmer, Paul. 1992. *AIDS and Accusation: Haiti and the Geography of Blame*. Berkeley: University of California Press.
- Fenno, Richard F. Jr. 1978. *Home Style: House Members in Their Districts*. Boston: Little, Brown.
- Joseph, Steven. 1992. *Dragon Within the Gates: The Once and Future AIDS Epidemic*. New York: Carol and Graff.
- National Hemophilia Foundation. 1982. *Hemophilia Newsnotes*. July 14.
- _____. 1984. Chapter Advisory #14. *Hemophilia Information Exchange: AIDS Update*. February 3.
- _____. 1984. Medical Bulletin #10/Chapter Advisory #13. *Hemophilia Information Exchange: AIDS Update*. January 24.
- _____. 1984. Medical Bulletin #14. *Hemophilia Information Exchange: AIDS Update*. January 30.
- Nussbaum, Bruce. 1990. *Good Intentions: How Big Business and the Medical Establishment Are Corrupting the Fight Against AIDS, Alzheimer's, Cancer and More*. New York: Penguin Books.
- Perrow, Charles and Mauro Guillen. 1990. *The AIDS Disaster: The Failure of Organizations in New York and the Nation*. New Haven: Yale University Press.
- Shilts, Randy. 1987. *And the Band Played On: Politics, People and the AIDS Epidemic*. New York: Saint Martin's Press.
- Stine, Gerald. 1995. *AIDS Update 1994-1995: An Annual Overview of Acquired ImmuneDeficiency Syndrome*. Englewood Cliffs, NJ: Prentice Hall.

Concerning the Speaker

Patricia Siplon, the daughter of two Naval officers, was born on Guam and lived in a variety of states before the family settled in Idaho. She attended Utah State University, where she received a B. S. in biology and an M. S. in political science. In 1997 she completed her Ph.D. in politics from Brandeis University.

Patricia's exposure to health policy issues began in 1987 when she was awarded an L. B. Johnson Fellowship to work as an intern on Capitol Hill in the office of Richard Stallings (D-Id). While studying for her doctorate, she worked with several AIDS organizations in the Boston area in both a professional and volunteer capacity. Over a seven-year period, her roles have included: policy analyst, conference organizer, needle exchanger, switchboard operator, client resource librarian, and client support team member.

As an assistant professor in the Political Science Department, Patricia has worked to promote greater student participation and activism. She is a member of the Student Life and Media Committee, advisor to the Political Science Club, which took its first-ever trip abroad in 1998, and faculty liaison to Student Government. This year she was the recipient of the first annual Student Government Faculty Recognition Award.

Concerning the Lecture

The premise of the Final Word Lecture is that the lecturer has only six months to live and would like to sum up a career of teaching and scholarship for colleagues, students, and friends. While the selected professor is, in fact, healthy, the hypothesized death adds urgency and focus to the lecture. The idea is borrowed from the University of Michigan's "Last Lecture."

The Final Word Lecture is given on the evening of Wilkes University's Faculty Recognition Day, at which faculty are lauded for their achievements as teachers and scholars. A number of awards, including the Carpenter Award for teaching, are announced at this annual event.

The Final Word lecturer is chosen by a committee of Wilkes professors and receives a \$1,000 award through the generosity of an anonymous donor. At a subsequent time, and at the donor's discretion, the title of the award and lecture series will be changed to include the donor's name.

Previous winners were:

- 1993 James L. Merryman
Reinventing Humanity for Survival in the Twenty-first Century:
Salvaging Our Best through Prehistory and Multiculturalism
- 1994 Dennis P. Hupchick
Nation or *Millet*? Contrasting Western European and Islamic
Political Cultures in the Balkans
- 1995 Donald R. Brand
Multiculturalism Revisited
- 1996 No lecture given
- 1997 Jane M. Elmes-Crahall
Rhetorical Savvy and Political Civility

