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Volume III

Robert K. Bolan, M.D.  MEDICINE, ACTIVISM, AND THE GAY COMMUNITY IN SAN FRANCISCO

William F. Owen, Jr., M.D.  AIDS CLINICAL PRACTICE IN THE PRIVATE SECTOR

With an Introduction by
Donald I. Abrams, M.D.

Interviews Conducted by
Sally Smith Hughes, Ph.D.
in 1996

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Robert K. Bolan, M.D., (b. 1946). General Practitioner and AIDS Activist; background and early career; pre-AIDS work with the National Coalition of Gay Sexually Transmitted Disease Services [NCGSTDS] and Bay Area Physicians for Human Rights [BAPHR]; early speculation on cause of AIDS: immune overload, cytomegalovirus and Amyl Nitrate; Marcus Conant; AIDS activism with. San Francisco AIDS Foundation, Kaposi's Sarcoma Research and Education Foundation, various other organizations; early AIDS symptoms and treatment protocols; creating guidelines for safe sex; William F. Owen, M.D., (b. 1949). Primary Care Doctor and founder of BAPHR; background and early career; founding BAPHR before the AIDS epidemic; defining AIDS; early incidence of AIDS-related opportunistic infections: Pneumocystis pneumonia, lymphadenopathy, Kaposi's sarcoma; AIDS medicine and early AIDS drugs, treatments; San Francisco County Community Consortium; San Francisco Medical Institutions' response to the AIDS epidemic.

Introduction by Donald I. Abrams, M.D., Chair, Community Consortium.

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Robert K. Bolan
First, transport yourself back in time to the late 1970s, early 1980s, when solo medical practitioners were the norm in the San Francisco Bay Area. Community physicians, practicing alone in their private practices, were the first to encounter patients with the unusual purple lesion or the rapidly progressive pneumonia. Many of these providers had much in common with their patients—their age, their socioeconomic status, and their sexuality. Even before the establishment of the AIDS clinics at the university facilities, the community physicians were on the front lines as the epidemic erupted. They were truly community providers not only in the contrast to the academicians, but also often as members of the community that was about to become decimated by the ravages of the terrifying new disease. Has such a situation ever before been encountered in the history of medicine?

Recall as well the history of the "Gay Liberation" movement in the United States. In the late seventies, homosexual men and women were just becoming comfortable with emergence from their closets, enjoying an openness and sense of empowerment that accompanied the newfound freedom and acceptance. Nascent organizations of lesbian, gay, and bisexual physicians were being established, initially with the founding of the Bay Area Physicians for Human Rights (BAPHR) in 1977, followed by the national American Association of Physicians for Human Rights (AAPHR [now the Gay and Lesbian Medical Association—GLMA]) in 1981. In fact, it was at a BAPHR meeting of gay physicians from around the country being held in San Francisco in June 1981 that it became evident that these unusual cases of Kaposi's sarcoma and Pneumocystis carinii pneumonia were more than freak isolated occurrences. These organizations served as early foci for information dissemination and educational efforts to alert colleagues and government health officials about the new disease. BAPHR and AAPHR meetings became informal support groups in a way, providing community physicians with a safe haven to share the sense of fear, frustration, and loss that accompanied caring for their earliest AIDS patients, even before the disease was named or the cause was discovered.

Despite an attempt to centralize care of AIDS patients at a center of excellence at San Francisco General Hospital (SFGH), community physicians maintained a desire to care for their patients in their own practices. After all, it was a brand new disease. It is not as if there were a fountain of information on how to treat it that only flowed at SFGH. Although most of the earliest clinical trials evaluating immune modulators and later antiretrovirals were occurring at the General, providers chose to maintain their primary caregiver role. They were undaunted by the novelty of the disease. They were unhampered by the lack of specialty training since there was no such thing as an AIDS
Read now the stories of some of the generals on the front line in this war. Although not himself a member of the gay community, Jim Groundwater was a favorite dermatologist in private practice for BAPHR physicians to consult. He likely saw the city's first case of Kaposi's sarcoma. Bob Bolan, Jim Campbell, Bill Owen, and Ric Andrews were providers on the front lines, tending to both the medical and psychiatric needs of the community under siege. Stephen Follansbee, completing his infectious disease fellowship just as the initial cases of Pneumocystis carinii pneumonia were diagnosed, became one of the first of the new breed of AIDSologists, his entire early career devoted essentially to the treatment and investigation of the new disease. Another investigator involved in attempting to crack the code from the perspective of the epidemiologist was Paul O'Malley, searching for clues in stored serum specimens and serial follow-up of a cohort of gay men who had been enrolled in a local hepatitis B vaccine trial in the late 1970s. All of these individuals made significant, too often unsung, contributions in the very early days of the epidemic and have for the most part continued on the same course to the present day.

In 1985, Mayor Dianne Feinstein asked Paul Volberding, the director of the AIDS program at San Francisco General Hospital, to establish a line of communication with the community providers caring for patients with AIDS in the Bay Area. The first meeting of the dozen or so providers was held in March at the San Francisco Medical Society. Seeing that many of those in attendance were from the gay community, Paul came to me and suggested that perhaps I should continue the dialogue with these physicians, many of whom he knew to be my friends from BAPHR. Links to my BAPHR colleagues had previously proven very valuable during my oncology fellowship when I established in 1981 a cohort of men with persistent generalized lymphadenopathy to follow prospectively in a natural history cohort. Many of the subjects referred for evaluation were sent by the doctors whose stories follow.

It was my pleasure to preside at the next meeting of the community physicians' group, which was initially formed for a number of reasons.
Information exchange was essential in these early days of emerging therapies. As well, we at the SFGH facility saw this meeting as a way to inform the community providers about ongoing research protocols to which they could refer their patients. As the group was a coming together of community physicians and those from the county hospital, County Community Consortium seemed an appropriate moniker. (In time the acronym CCC could never be correctly decoded by those who tried to use the organization's full name, so it was shortened to Community Consortium.)

Within the first year of meeting, it became clear that County Community Consortium providers were interested in taking a more active role in learning how best to care for their patients with the new disease. If memory serves me right, I believe it was Jim Campbell who raised his hand at a meeting and said, "You know, instead of sending all of our patients to SFGH to participate in clinical trials, there are questions we can answer in our own offices." That observation led to the development of a consensus protocol on how to prevent a second episode of Pneumocystis carinii pneumonia [PCP] in patients who had already experienced a first episode. Each provider had their own favorite regimen. Some offered no prophylaxis. Rather than depend on anecdote, we worked to develop a randomized clinical trial that was launched in July 1986 as perhaps the first community-based clinical trial in HIV disease. Soon after its inauguration, the trial was thwarted by the release of the first antiretroviral agent--AZT--because the first patients to receive the product were cautioned not to take any other non-essential medications by mouth. Since patients with a prior episode of PCP now had access to a potentially life-extending antiviral agent, interest in oral prophylaxis against a treatable pneumonia waned.

Undaunted, Consortium physician/investigators next designed a study to investigate PCP prophylaxis using the inhaled pentamidine therapy which had been developed by a UCSF/SFGH pulmonologist. Working together on the inhaled pentamidine protocol, town and gown investigators collaborated in a manner that would become a model for future productivity and success in conducting clinical trials in the sites where patients received their primary care. Ultimately the Consortium's aerosolized pentamidine trial would lead to FDA approval of the modality as the first prophylaxis for an HIV-related opportunistic infection as well as a lead article in the New England Journal of Medicine. It was clear that significant research could be done outside of the hallowed hallways of academic teaching hospitals. This Consortium achievement became a model for community-based clinical trials programs later established by both the American Foundation for AIDS Research and the National Institute of Allergy and Infectious Diseases.

Much of the success of the Community Consortium and even the larger San Francisco Model of HIV care can be traced to the efforts of
the physicians whose stories follow. No such collaborative coming together of the community was seen in other areas hard hit by the epidemic. New York and Los Angeles did not pull together the way the community did in the Bay Area. It can be attributed as well to the collaborative congeniality fostered by BAPHR, allowing its member physicians to strike out united against the common enemy--the disease--and not against each other.

I myself owe much of my professional as well as personal growth to my colleagues you are about to meet. Serving as brave, openly gay role models for a young junior faculty academic, initially fearful of coming-out to avoid derailing my career, the examples of these noble, proud and successful professionals inspired my ensuing openness. I write this today with pride as the current president of the Gay and Lesbian Medical Association. Through two decades of battle, these brave warriors on the front line of the fight have unique stories to tell of a struggle to save their community from a plague that often brought as much political as medical despair. Although the battle is neither won nor over, the contributions of the community physicians have done much to enrich the lives of their patients, the medical profession and society-at-large. Has such a situation ever before been encountered in the history of medicine?

Donald I. Abrams, M.D.
Chair, Community Consortium
Assistant Director, Positive Health Program
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Professor of Clinical Medicine
University of California, San Francisco
President, Gay and Lesbian Medical Association, 1999-2000

January 2000
San Francisco, California
SERIES HISTORY--Sally Smith Hughes, Ph.D.

Project Origin and Organization

This series with community physicians is the third phase of an oral history project documenting the medical response of the medical and nursing professions in the early years of the AIDS epidemic in San Francisco. Please see the earlier volumes for descriptions of the particulars of these two previous interview phases.

Phase one and two with university physicians and nurses has effectively, albeit selectively, documented the role of academics in the epidemic, the "gown" component of the traditional town and gown division of medicine worldwide. What was obviously missing were accounts by representatives of the "town," that is, physicians with private practices in a variety of medical specialties relating to AIDS. In 1995, UCSF Library, represented by Karen Butter, now Acting Director, came to the rescue with a grant to the Regional Oral History Office to conduct interviews with community physicians whose practices included substantial numbers of AIDS patients early in the San Francisco epidemic. The grant was sufficient to cover two- to six-hour interviews with seven individuals--six physicians and one professional in the San Francisco Health Department--selected because of their substantial participation in the early medical response to the epidemic. In 1996, interviews were recorded in the San Francisco offices of the participants. The only exception were the interviews with Dr. Robert Bolan, which took place in Glendale in southern California, his new home after a recent career move.

Primary and Secondary Sources

The interviews were largely based on the reading I had done to prepare for the first two phases of the project, and even more substantially by the information I had acquired in the course of these interviews. The most significant new source for phase three was documentation concerning Bay Area Physicians for Human Rights [BAPHR], a gay physicians' organization founded in San Francisco in the late 1970s. An extensive series of "The BAPHRON," BAPHR's informative monthly newsletter, and documents in BAPHR's office in the Castro District of San Francisco were rich sources of information on the response of gay physicians and the gay community to the epidemic.

Selected Themes

BAPHR has a large voice in the present series. Five of the seven interviewees were at one time or another members of BAPHR and spoke at length of the organization's contributions. Only James Groundwater, who
is not gay, and Paul O'Malley, who is not a physician, were never members. Furthermore, BAPHR was one of the focal points of the early medical response to the new disease after it was recognized in San Francisco. Its members came to the crisis with the very intersection of experiences that the epidemic seemed to demand: medical skill in diagnosing and treating diseases prevalent in gay men, and sympathy for preserving the personal and sexual freedoms that the gay community had recently won. The vast difference for physicians confronted with previously healthy young men who were suffering and dying from AIDS was that neither cause nor treatment of the mystifying new disease was known and available. These histories recount over and over, but from diverse perspectives, the ways in which physicians responded professionally and personally to the increasing stream of very ill patients with puzzling symptoms and psychological as well as physical problems. They also trace physicians' gradual awareness of the severity, extent, and complexity of the new epidemic, focused initially so frighteningly on gay men. Some of the interviewees also tell of learning to manage the "worried well" who came to their physicians with fears of acquiring or transmitting the new syndrome.

Aside from providing a portrait of AIDS medicine as practiced in private medical offices in the years before AZT and protease inhibitors were available, these interviews describe from a variety of perspectives, the interviewees' responses to major events and crises of the epidemic in the early 1980s. A pervasive theme is the formulation of safer sex guidelines. Bob Bolan particularly, but others as well, were preoccupied with the formulation of guidelines which would simultaneously reduce disease transmission and honor the community's arduous battle for freedom of sexual expression. The accounts are sometimes explicit about sexual practices and attitudes, showing how those active in the epidemic brought taboo issues out of the closet and onto the public stage. In fact, these oral histories suggest that one lasting effect of the AIDS epidemic may be to have made safer sex practices and healthy sexual expression an open topic of discussion in many sectors of American society. The histories offer an intriguing range of viewpoints on this issue in gay politics.

The interviewees also provide accounts of important events in the years closely preceding and following the recognition of AIDS in San Francisco--the deaths of San Francisco Mayor George Moscone and Supervisor Harvey Milk (the latter the first openly gay elected official in the country), the hepatitis B vaccine trials, the crisis over bathhouse closure in San Francisco, controversy over blood donation policy, fears regarding the AIDS antibody test, and so on. Most of these events highlight the intersection of medicine, sexual and gay politics, and human rights, as well as the strengths and fallibilities of individual human actors. The oral histories in this series are rife with colorful examples in all these regards. Readers may be interested
to compare these accounts with those of the university physicians and nurses interviewed for this project.

These comments only begin to tap the range of topics and insights embedded in all three phases of this project. My hope is that these interviews, over thirty in all, will provide a basis for ongoing documentation of the epidemic. Victoria Harden and colleagues at the National Institute of Health Historical Office have recorded the contributions of researchers at NIH and Ronald Bayer and Gerald Oppenheimer at Brooklyn College have interviewed physicians in various cities across the United States. But there is a great need to expand documentation in time and geography. To my knowledge, there is no systematic and sustained work on the history of AIDS in developing countries in which it is expanding at a terrifying rate. Neither are there indepth historical projects on specific topics, such as efforts to develop AIDS vaccines and the associated ethical and social issues. Perhaps this collection of oral histories will serve as an impetus and inspiration for others to pursue the history which remains to be recorded worldwide.

Locations of the Oral Histories

The audiotapes and bound volumes of all oral histories in the AIDS series are available for research at UCSF Library's AIDS History Project Archives. The oral histories are also available at the National Library of Medicine, the Bancroft Library, UCLA, and other research libraries. Some are available on the Internet at: http://www.lib.berkeley.edu/BANC/ROHO/ohonline. The remainder are in the process of being placed online.

Acknowledgements

We are grateful to Karen Butter, Acting Director of UCSF Library, for arranging project funding. I also wish to thank Dr. Robert Bolan for giving me access to three cartons of his personal records which he then donated to the AIDS History Project at UCSF. I also wish to thank Dr. Ric Andrews for arranging access to documents in the office of Bay Area Physicians for Human Rights.

I thank editorial assistants Grace Robinson, Julia Rechter, and Celeste Newbrough, and production manager Shannon Page for their efforts in finalizing the oral histories. I am grateful as always to Willa Baum, ROHO director, for her oversight and helpful comments.

Sally Smith Hughes, Ph.D.
Research Historian and Project Director

January 2000
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THE SAN FRANCISCO AIDS ORAL HISTORY SERIES

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John S. Greenspan, D.D.S., Ph.D., "AIDS Specimen Bank, UCSF"

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Helen K. Schietinger, R.N., M.F.C.C., "Nurse Coordinator of UCSF's First AIDS Clinic"

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Robert K. Bolan, M.D.
MEDICINE, ACTIVISM, AND THE GAY COMMUNITY IN SAN FRANCISCO

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Dr. Robert K. Bolan, 1983.
INTERVIEW WITH ROBERT K. BOLAN, M.D.

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Bolan's Greatest Contribution to the Epidemic 102
Robert Bolan was interviewed for the AIDS series because of his early, ongoing, and passionate involvement as a private family practice physician in many aspect of the AIDS epidemic, first in San Francisco and more recently in Los Angeles. Bolan describes in the oral history how he was in a sense "prepared" for the epidemic by his involvement in the 1970s with the first stirrings of the gay medical movement, particularly in association with the National Coalition of Gay Sexually Transmitted Disease Services. Like others interviewed in this project, he was troubled by the high incidence of sexually transmitted diseases in homosexuals and the casual use of antibiotics to treat them. His concern led to collaboration with the Centers for Disease Control, which was tracking disease in homosexuals, and in the production of a pamphlet outlining guidelines for gay sexual activity. Unknowingly, he was establishing a network and a background of experience which was to serve him well after the AIDS epidemic broke.

Predictably, Bolan threw himself, body and soul, into combating AIDS. He was a whirlwind of activity, taking on responsibilities in addition to his career in family practice. He tells of attending Marcus Conant's weekly study group which followed the Kaposi's Sarcoma Clinic at UCSF, and serving as a conduit (along with Steven Follansbee and others) for information flowing between university and community. The reader will find repeated herein many topics discussed in other oral histories in this series--learning of, speculating about, and defining AIDS; diagnosing and treating AIDS patients; working with Bay Area Physicians for Human Rights [BAPHR] and the San Francisco AIDS Foundation, and so on. Bolan invariably discusses these topics from his very personal and fresh perspective. (He is not adverse to using street language occasionally to add color to his remarks.)

One of the strongest themes of this oral history is Bolan's dedication to the production in the epidemic's first years of several versions of safer sex guidelines. (The word "safer" is deliberate; he and his co-workers did not wish to imply any 100 percent certain safety.) From his pre-AIDS experiences, he had learned the need to tailor the educational message about sexual practices in a way which gay men could hear and adopt. He and his colleagues struggled to compose guidelines which neither compromised personal safety nor the gay community's recently won sexual liberation. The task was not easy and his community was not universally appreciative.

One of the compelling interests of this oral history series with private medical practitioners is that although they shared a common experience as members of the gay community and of the even tighter group of gay physicians, each chose different ways to approach and cope with
the epidemic. If one were to select among them for drive, energy, and passion, the choice would most likely be Bolan. The reader will catch his energy and intensity between the lines, factors in his near-collision with emotional breakdown in the early years of AIDS.

The Oral History Process

Although two interviews were initially planned, Bolan made time for three when it became obvious that his many activities in the early epidemic required full coverage. The three interviews, interrupted several times by calls from patients, were conducted on August 13, 14, and 15, 1996, in a motel room in Glendale, California, which Bolan and his partner kindly arranged for me. Bolan had recently moved to Glendale to take up positions as Associate Professor of Clinical Family Medicine and Director of HIV Services at the University of Southern California. Bolan's articulateness, humor, and excellent recall, plus the three cartons of personal correspondence that he made available to me and subsequently donated to the AIDS History Project at UCSF, immensely enriched the interviews. The reader will find some of these documents referred to in the footnotes and/or placed in the appendix. Bolan returned the interview transcripts with a few corrections and editions.

These interviews, and others in this series, add factual detail to the historical record of AIDS in San Francisco; they also add poignant insight into personal character and experience. Asked for his greatest contribution, Bolan paused and then said:

Persistence. Showing up. And an attempt to approach this disease from a multifaceted approach: from an educational approach, from a social activism approach and community activism approach, and finally from a medical approach. That's it.

Sally Smith Hughes, Ph.D.
Research Historian and Principal Editor

February 2000
Regional Oral History Office
The Bancroft Library
University of California, Berkeley
**BIOGRAPHICAL INFORMATION**

*(Please print or write clearly)*

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I CAREER BEFORE THE AIDS EPIDEMIC

[Interview 1: August 13, 1996] ##
[San Francisco, California]

Education

Hughes: Dr. Bolan, let's start with where you were born and educated.

Bolan: I was born in Detroit, Michigan, and after a couple of years we moved to a small town in Michigan outside of Flint called Swartz Creek. I grew up there, went to high school in Flint for two years. Then we moved to Southfield, which is a suburb of Detroit, and I finished high school there. I went to the University of Detroit for undergraduate education, and graduated in 1964. Went to medical school at University of Michigan in Ann Arbor, and graduated in 1968. Went to do my internship or the first year of my family practice residency in Madison, Wisconsin [St. Mary's Hospital Medical Center, 1972-1973].

Sexual Orientation and Marriage and Divorce

Bolan: In my senior year at University of Detroit, I joined the theater department and composed a lot of the music for some of the plays for that year. During that process, I discovered that I wasn't completely heterosexual. I had other interests. I didn't even put a label on it. This is back in 1969, 1970, so there wasn't really a whole lot of terminology that I could turn around and identify with.

1## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.
Hughes: And it was the Midwest.

Bolan: It was the Midwest.

So when I began to acknowledge my sexuality, initially I didn't try to label it; I was just trying to understand it. At some point, I think I acknowledged that I was probably gay, but that I was at a point in my life and in history and in the Midwest and so on and so forth that I thought that I was going to "beat the rap." I was probably one of the last generations of people who really tried to "beat the rap" in large numbers.

So I joined the masses of the ignorant and uninformed and got married in my third year of medical school and had a son, thinking that I was going to escape into marriage. I knew that that was a disaster almost that day. It was terrible, it was just terrible. I persisted in trying to make a go of it, but it just became increasingly obvious that that wasn't the right thing.

Hughes: How long were you married?

Bolan: We separated during my internship, so that's about two and a half years. That was a very difficult time, because we were in Madison, Wisconsin, and her home was in suburban Detroit, Michigan. Large family—that's where her support was, and we'd moved to another state. It was across Lake Michigan. And we had a son.

I officially came out during my internship. That's when I began to have more sexual experimentation and experiences, and in pretty short order, met my first lover, and just fell head over heels in love. The poet or the literary figure who said, "It was the best of times; it was the worst of times," pretty much encapsulated that period of my life.

So as a result of the tumult in that first year of my internship, I dropped out of my program. I decided that I couldn't continue, because I was just too distracted, too screwed up. I was still very closeted and in the process of coming out. I had the good fortune that my first lover was a marvelous man and full of a sense of himself and his rightful place in the universe, both intellectually and emotionally. He was really a role model for me, even though he was younger than I. I really owe him a great deal.

Hughes: Had he come out?

Bolan: Yes, after a fashion. [laughs] You know, all of us were out after a fashion in those times. Something happened to him in
Hughes: Well, you told me in the car, if I may paraphrase, that because you had been through the process, you in a sense were readier to become active in the epidemic than some of your colleagues, who were still coming out.

Bolan: I wouldn't want to presume to speak for where anybody else was in their own personal coming-out process, but yes. Before the AIDS epidemic came, I had a sense of myself, and I think I owe it in large part to that first relationship--partly Jay, partly me, partly the environment of Madison, Wisconsin, a very liberal community, a college town through and through. And there was a pretty active network of gay people there. I became immersed in that through him, and it was a good experience.

Hughes: It never shook your confidence in pursuing medicine as a career?

Bolan: No, it didn't. Well, you know, I think maybe there was a brief time where I was shaken. I worked in an emergency room, and then I joined a private practice in northern Wisconsin--Wisconsin Dells, and found out after about nine months of that that I felt poorly trained for the rest of my career, didn't really quite know what I wanted to do, then went back to Madison and did full-time emergency medicine for a year. After that, I finally had my goals on straight and decided that I would go into family medicine. But during that process, there was a lot of self-doubt and questioning, not so much was I worthy of medicine, but whether I could focus sufficiently on it, give it its due.

Hughes: Then what happened?

Bolan: When I started my residency [St. Michael Family Practice] in Milwaukee in '75, that was really the beginning of my awakening to the problems of sexually transmitted diseases in sexually active gay men. I'd say it was probably not until about '76 that I really started to have that awareness.
Interest in Sexually Transmitted Disease in Gay Men

Clinic Volunteer

Bolan: In about '76, I met Mark Behar, who was the chairperson for the National Coalition of Gay Sexually Transmitted Disease Services, the organization that put out the brochure, "Guidelines and Recommendations for Healthful Gay Sexual Activity," a very 1970s politically correct title, I might add. [laughter] Mark seduced me into becoming medically active in gay sexually transmitted disease problems. He was the one that recruited me to come to the gay VD [venereal disease] clinic in Milwaukee. It's funny that I really don't have a clear memory of how we first met, but it was obviously a very seminal thing in my life, because it set me on a straight-line path right until the present moment.

Hughes: And atypical for family practice?

Bolan: Well, I don't remember at the time whether it was atypical. Today it certainly is not atypical for residents during their residency to volunteer someplace. As a matter of fact, I think it was pretty typical back then too, because I remember volunteering in nongay VD clinics and there being other medical students there as well. But not everybody did it; we're talking about maybe 10 percent or less of the graduating classes.

Once I got into volunteering, I just got pulled in instantaneously. I became almost an immediate convert, like I'd found a mission or a niche or a need that was crying out for me to become involved in. It didn't take very long at all for me to understand a couple of really key things. First of all, that there was really a problem with sexually transmitted diseases in the sexually active gay population, and number two, that organized medicine, mainstream medicine, had no knowledge, very little interest, and what contact they would have with people with sexually transmitted diseases usually resulted in very unpleasant outcomes for the patient, very cold and unfeeling.

Hughes: For all sexual orientations?

Bolan: Well, I can't speak to all sexual orientations because I was immersed in this particular one. I'm sure that the stigma of STDs in general was there, but there was a double dose of contempt doled out for those who got their STDs in "unnatural" ways. It was such a formative experience for me, because I had the opportunity to see young men who were essentially my same-age peers, and who were mostly not different from me much at all. So
I got to know them as people in a setting of a community-based organization that was built for gay people. At that time in history, it was just a very warm and welcoming haven.

**National Coalition of Gay Sexually Transmitted Disease Services**

Hughes: Was this the infancy of--can you call it a gay medical movement?

Bolan: Yes, oh, absolutely.

Hughes: When was this?

Bolan: This is 1977. This group, the NCGSTDS, National Coalition of Gay Sexually Transmitted Disease Services, was really the first national organization. It's exactly what its name says.

Hughes: Very descriptive.

Bolan: Very descriptive.

Hughes: How did it work?

Bolan: I'll take you through the tortured logic of the name. We didn't want to restrict participation and membership to those clinics that did testing and treatment; anyplace that did services directed toward sexually transmitted diseases was eligible to join. It was an organizational model that attempted to bring as many people that were doing sort of the same thing together, so that they could build on each other's successes and learn from their mistakes and so on and so forth. I can't tell you all the groups that participated in it, but I know Denver Metro Clinic did, and the Howard Brown Memorial Clinic in Chicago was a member. I think the Boston Fenway Clinic was a member. And then there was a group in Philadelphia, maybe a couple of others.

It was formed because the storm clouds that were gathering on the horizon in the mid-seventies were the storm clouds of rapidly increasing STDs. In 1976 or '77, the CDC [Centers for Disease Control] reported that the majority of cases of early syphilis in the country were in men who had same-sex partners, men who named men as partners. We had the highest syphilis rate in the country.
Centers for Disease Control Tracking of Disease in Gay Men

Hughes: How long had the CDC been tracking diseases in gay men?

Bolan: I think for a long, long time. When did public health, STD epidemiology, case-finding, begin? When did they start to do partner notification and partner identification?

Hughes: I don't have the answer. Do you?

Bolan: No, I don't, but it's knowable. [tape interruption]

Hughes: I wonder if the CDC kept statistics that were specifically related to gay men.

Bolan: They may not have been. When was the Summer of Love in San Francisco?

Hughes: Late sixties.

Bolan: Then I'll say it was 1968. Maybe it was '69. I remember having a conversation with Selma Dritz\(^1\) from the San Francisco public health department in 1980, '81, or something like that. She attributed the rise in STDs in the gay population to the Summer of Love. That's when she marks the beginning, and she did because in that year they had an epidemic of Shigella or something like that, or maybe it was an epidemic of hepatitis A, I don't remember. But it was a significant rise in a reportable disease that she points to as the beginning. And it was in fact when the influx of gay people began to happen.

Hughes: Stonewall was '69?

Bolan: Stonewall is '69, yes. So it started all around that same time. And I think that the free love and the hippy movement was a comfortable envelope to contain the early gay movement. Not that it was necessarily supportive of it, but it was a comfortable, permissive envelope.

Back to the question of when did the CDC start looking at gay STDs specifically. Part of the answer would depend on when

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the epidemiologists made a conscious decision to begin to ask their questions of people in a much more supportive and nonjudgmental manner, and I don't know when that was, but I would guess that we're talking probably the mid-sixties. Because by 1972, there was already an awareness not only that syphilis was rampant in the gay community, but also hepatitis B. That's the second signal, sentinel epidemiological event.

Bolan's Collaboration with CDC

Hughes: You mentioned working with the CDC.

Bolan: Yes. That came to be primarily through the efforts of David Ostrow, because David, as the medical director of the Howard Brown Memorial Clinic in Chicago, had been working on the hepatitis B cohort and had some money from the CDC to do that. He found himself that connection. David was an extremely energetic, and still is an extremely energetic individual. He kind of made things happen.

Hughes: The CDC were perfectly willing to extend themselves this way?

Bolan: Yes, they were. And this is, I think, a key point in understanding the importance of groups like the NCGSTDS, and the importance of community-based organizations. The fact is that the Centers for Disease Control have always considered the states their partners of first choice. That goes back to the separation of the feds and the states. The CDC is a very traditional governmental organization that says, "Our clients are the states. We don't get involved in the local level. That's not our business."

But the epidemiologists that made up the CDC recognized that the states weren't doing jack shit in STDs for the gay community. The people at the CDC recognized that there were these community-based organizations that were springing up around the country that were in fact doing the business of gay STDs and were forming alliances with their local public health departments to get microbial culture services, blood testing services, and volunteers to come in and see patients. So the CDC recognized very early on that if they were going to get an "in" in the information about STDs in the gay community, that they'd best partner with these community-based organizations.

Hughes: So again, you've got a network that is laying the groundwork for the epidemic, would you say?
Bolan: Yes, it's true. I hadn't thought about it that way. I don't know if the CDC had done that in other instances before.

As I say, I think it's a really key thing that formed that alliance. And the goodness of the fit was demonstrated by the almost immediate level of comfort and trust that developed between the community folks and the CDC folks. It was an example of two groups of people coming to focus on a problem, looking at the problem, looking at each other, rolling up their sleeves and saying, "Where do we start?"

I remember having conversations with Paul Wiesner, who was the director back in '77 through I believe '79 or so of what was called, at that time, CDC's VD Control. It's undergone so many different name changes, I don't know what it is now. But talking to him and his other colleagues was just like talking to colleagues; they treated us like respected colleagues. That was so refreshing, couldn't help but get our support. You know, treat us like real people doing important work, and we're going to work with you. So that was a very important development that I think did lay the groundwork for the epidemic.

Rise in Sexually Transmitted Disease in Gay Men

Bolan: From '72 to about '77, '78 or so, there was active research going on to develop a hepatitis B vaccine. They began to enroll patients, I believe it was in '72, and I think the end of the study was five years later. Maybe it was a little bit longer. In San Francisco, they were having a hard time finding candidates for the hepatitis B vaccine because the vast, vast majority of sexually active gay men that were being tested already had been exposed to hepatitis B or were carrying it. The seroprevalence rate for hepatitis B antibody was 78, 80 percent. And the rate of hepatitis B carriers was somewhere between 5 percent and--I want to say 10 percent--I don't think that's right, but it was alarmingly high. So we had an epidemic of hepatitis B.

Those were the storm clouds that were gathering on the horizon a good eight, nine years before the first clinical HIV case popped into the scene.

Hughes: Was it a cause for discussion and comment?

Bolan: Absolutely. And that's why the NCGSTDS came into being in the first place. So when I was back in Milwaukee in 1977 looking at this burgeoning STD caseload, I was alarmed; David Ostrow in
Chicago at the Howard Brown Memorial Clinic was alarmed; Dan William in New York was alarmed. We were all very concerned and alarmed about this, not because we had any prescience of what was coming, but people died of hepatitis B, for Christ's sake. Ten percent of cases of hepatitis B at that time would go on to become chronic.

Cavalier Attitude towards STDs

Hughes: And yet, I've heard from some of your colleagues that along with this angst is a happy-go-lucky attitude: you've got an STD; go in and get an antibiotic and that takes care of it. It wasn't an atmosphere that caused people to stop and think, Do I really want to continue the way I have?

Bolan: Yes, there was that.

I'm not aware of other organizations besides the NCGSTDS that were trying to network nationally, trying to work with the Centers for Disease Control as its primary collaborative partner. I'm not aware of other groups that were doing it on a grassroots basis. So in all humility, I would have to say that those who were not involved in this particular movement, if you will, were not concerned, hadn't thought through the ramifications, and were people who were taking the happy-go-lucky, there's a shot for this, there's a shot for that, don't worry, be happy route.

Pamphlet: Guidelines for Gay Sexual Activity, 1981

Bolan: In fact, this guidelines document that we finished in 1981, we began working on in 1979.¹ Let me see. [looks at pamphlet]² Yes, we started it in '79; says so right here. [interruption] I thought there was a more expansive reference to the fact that everything didn't have a cure, and the only line that I can find

¹ "Guidelines and Recommendations for Healthful Gay Sexual Activity," modified and edited by Robert K. Bolan, 1981. See the copy in the appendix.

² Dr. Bolan brought to the interviews three cartons of personal papers which he later donated to the AIDS History Project, UCSF Library.
on a quick perusal is, "Not all diseases have the same treatment. Penicillin does not cure everything."

What we tried to do with this document was to list all of the various STDs as we knew them and to honestly tell people what we knew about what behaviors put them at certain risks, to educate people with clear information. If you read this document, you understand that it comes from a health-education perspective of respecting your listener, which means not approaching them with any kind of a moralistic undercurrent to your message. You state as clearly as possible what the risks are and with what degree of certainty you know those risks, so that people can make the most informed decisions. It was our attempt to get the importance of STDs on the agenda.

##

Bolan: I initially described the first meeting of this organization [NCGSTDS] that started the dialogue that led to these guidelines in 1979 in my paper. It was at a scientific meeting. In my 1989 paper I said when the guidelines were finished and ready for distribution in 1981, that already the virus HIV had been incubating in the community for at least four years, and that we were about five years too late with this project. It's funny to think about that again, because it has a very profound emotional impact on me; we were working and toiling and trying to figure out how to deliver messages that people would hear and act on, and were pleased that we had enough common sense to do that. We believed our process was very carefully crafted, and our end product was going to be the beginning of this fabulous education campaign. But it was too late. When we all realized that, when the lightbulbs went on one by one, we all felt very bad.

Hughes: Yes, in an ultimate sense it was. But on the other hand, if you hadn't had that experience, think how much longer it would have taken you to get off the ground when AIDS was recognized.

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2 Current Aspects of Sexually Transmitted Disease, probably held in Chicago, 1978.

Bolan: Yes, it's true.

Hughes: Was this network called into action in the epidemic? Did those clinics or organizations become players?

Bolan: Oh, absolutely they did.

Hughes: Think how much longer that would have taken if you'd had to establish contact and trust.

Bolan: Sure. One of the things that I've got in one of those boxes are all of the NCGSTDS newsletters. Mark was a prolific writer, and he wrote these wonderful, wonderful newsletters. There's a really rich treasure trove of information in those as to what the national response was as we went from just dealing with STDs to dealing with AIDS. To my mind, the best historical documents are Mark's newsletters.

But you're right: the initial people who sprang into action with the epidemic were those that were doing this initial work.
II THE AIDS EPIDEMIC

Bolan's Arrival in San Francisco

Bolan: I came to San Francisco in 1979--

Hughes: Why did you?

Bolan: Well, in 1978, I met my current lover, Tim Strahl. I was practicing in Hartland, Wisconsin—not heartland, but in many ways, it's the heartland, too. It's very typically Midwest. I was practicing in a general practice in Hartland, which is about thirty miles west of Milwaukee. And once a week, I would drive in to Milwaukee for the gay VD clinic night.

As my interest in that endeavor grew, I began to realize that there was this really major schizophrenic dichotomy in my life. So it was a combination of wanting to find myself a venue where I could marry those two activities and not feel the opprobrium of my peers and so forth, because it was still only 1978 or '79, and I was sick and tired of the Midwest winters. In fact, what did it for me was one day, I was driving home in January or February, whenever the hell it was, and my car slid off the road and went into the ditch. I was wading through snowdrifts up to my armpits to get back to my house, and the lightbulb went on in my head and said, "Robert, you're a physician. You don't have to put up with this shit. What are you doing?" [laughter] So I packed up my new husband, put him in the car, and we drove to San Francisco.
Bay Area Physicians for Human Rights

Hughes: San Francisco because it was a gay center?

Bolan: Yes, because in 1979, it already had a pretty established presence and emerging community, and the Bay Area Physicians for Human Rights was already in process for two years.

Hughes: Did you know that at the time?

Bolan: I think I did, but I really don't remember whether I learned it after I made the decision to come to San Francisco or whether that was one of the deciding factors. But I can tell you, about thirteen minutes after I got to town, I found them. I called up David Kessler and asked him when and where the next meeting was. As soon as I became involved with BAPHR, I had one major thing on my agenda, which was to take the impetus that we had created with the NCGSTDS. I'm not sure exactly when in 1979 it was, but we had a meeting in 1979 in Chicago, and we decided at that meeting that we were going to have our second national meeting in San Francisco, because I was moving to San Francisco, and I was going to coordinate the conference.

So I came to town, I didn't know anybody, and I thought, Okay, what am I going to do here? So I teamed up with BAPHR, and I said, 'This is a nice organization; I'm glad to meet all these gay doctors; I feel really welcome here. But I've got some things I've got to accomplish, and I'd like BAPHR to be part of it and give me essentially a cloak or a mantel of the organization's respectability. Give me some recognition here.' They did that, and I organized, with the help of several other people, the second meeting of this group. It was kind of a subconference within a bigger conference, and the bigger conference was the National Gay and Lesbian Health Organization's national conference. I think it was the third one.

Hughes: Which was in San Francisco?

Bolan: In 1980.

Hughes: I have a note here that you were director of the symposium in Chicago in 1979.

Bolan: No, I didn't direct that one, David Ostrow did. I directed the one in 1980 in San Francisco. It was called "Current Aspects of STDs II," the first one being in 1979.
Learning of the AIDS Epidemic

Alvin Friedman-Kien's Report

Hughes: Did you go to the BAPHR conference in June of 1981, in which Alvin Friedman-Kien reported on cases of Kaposi's sarcoma in New York City?

Bolan: Oh, yes. This is the brochure for it. [The conference was] called "Medical Issues and Sexual Orientation."

Hughes: Is he listed as a speaker?

Bolan: No, he was added on later.

Hughes: Yes, that's why I asked.

Bolan: As I was looking through these boxes in a very cursory manner on Saturday and Sunday, I came across the program for this symposium. It's in here someplace, and it does have him on it. Yes, he was at this meeting.

Hughes: How did that come to be?

Bolan: Well, as you can see, this conference was June 26, 1981. This was literally thirteen days after the CDC's MMWR came out on cases later recognized as AIDS, it was June something.

Hughes: But that's the report on PCP [Pneumocystis carinii pneumonia], not on KS [Kaposi's sarcoma]. The KS report came out on July 3, 1981. So this conference occurred before anybody officially knew about the KS cases in young gay men. But there was an informal network, as you've already described.

Bolan: Of course.

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Hughes: I usually ask in these interviews, "How did you first become aware of the epidemic?" Angie Lewis said it was at this conference. Her impression was that Friedman-Kien's talk was somewhat of a rush job, because she remembers some slides that were hand-drawn, as though maybe he hadn't had time to have them professionally made.

Bolan: I think that's exactly right. I hadn't realized when I looked at the program that it was a last-minute thing, but now seeing this brochure and not having him here, I know it was.

Hughes: Who would have had a connection with Friedman-Kien?

Bolan: The name that comes to mind most readily is Marcus Conant, but Marcus wasn't involved in BAPHR. But that doesn't mean that he didn't communicate it to somebody. I remember that meeting very well. I do remember the rush to have Alvin come. The fact that the first [KS] case wasn't reported until July 7 just means that he was coming and telling us about it before it got published. Even though the CDC [MMWR] was pretty good about being like a newsletter, kind of right up to the minute, their lag time from when stuff happened until when they reported it was probably--I mean, if they really wanted to ramp something up and report it, it could be as short as a week.

Hughes: Can you describe Friedman-Kien's presentation?

Bolan: Well, the PCP cases had just come out in MMWR on June 5.

Hughes: Now, had you heard--

Bolan: Oh, yes. I first heard in I think it was April.

Hughes: How?

Bolan: I don't remember.

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1 See the oral history with Angie Lewis, R.N., in the AIDS nurses series.

2 See the oral history with Marcus Conant, M.D., in the AIDS physicians series.
A Meeting at St. Francis Hospital

Bolan: Another meeting that I remember was at St. Francis Hospital. It might have even been a meeting of the Bay Area Infectious Disease Society, because Steve Follansbee1 was there, and several of the other ID [infectious disease] folks in town. Steve Follansbee presented a case of CNS [central nervous system] toxoplasmosis. Steve has got probably the earliest paper on CNS toxoplasmosis in association with AIDS. And I don't remember when that meeting was.

CDC Meeting on Sexually Transmitted Disease, San Diego, May 1981

Bolan: I went to a regional CDC STD meeting, a state epidemiological meeting or something like that, that was held in San Diego.

Hughes: I think that was in May of 1981.

Bolan: All right, then my memory is correct; I heard about the outbreak in the spring. I remember walking along a sidewalk discussing it with--

Hughes: In San Diego.

Bolan: Yes, in San Diego, discussing it with the editor of the journal, Sexually Transmitted Disease, which published an editorial of mine, "Homosexual Sexually Transmitted Diseases: Focusing the Attack."2 Bill McCormack. It was published in October-December of 1981. But I remember having a brief conversation with him and some others about what this meant, the implications of it. In fact the last paragraph of that paper was added at the last minute, making references to the cases of PCP.

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1 See the oral history with Stephen Follansbee, M.D., in this series.
2 8:293-297.
Trying to Define the Outbreak

Hughes: How many cases of PCP were you aware of at that point?

Bolan: Just the few cases that had been reported in L.A. How many were there?

Hughes: There were five reported in the MMWR.

Bolan: They occurred in late 1980, I think.

Hughes: Some of them did, some of them didn't. One month [Michael] Gottlieb would get a case, and then a couple of months later he'd see another one. So if that meeting was late May, 1981, then all five cases must have been reported by that point.

Bolan: Yes. Even though it was before the MMWR came out, we each had a network.

Hughes: Was Gottlieb at the San Diego meeting?

Bolan: No, Gottlieb wasn't. This was a holdover from my STD days. This was my STD cohort.

Hughes: Was it the fact that these five cases of PCP were appearing in gay men that caught people's attention?

Bolan: Yes, immediately. It was the clustering of so many unusual things in a short period of time, and then followed quickly by that case of toxoplasmosis that I can't quite place in time, and followed quickly by Alvin Friedman-Kien coming and talking about Kaposi's sarcoma.

Hughes: Did you see connections among those cases?

Bolan: I don't remember when the first bright person said, "All of these things are connected." I do remember that very early on, that while we were trying to struggle to understand whether these disparate things could have anything to do with one another, we--

Hughes: That was discussed?

Bolan: I believe so, yes. I don't specifically remember that it was, though. It had to have been, because we were kind of buzzing and speculating about, What does all this mean? I mean, is this a fluke? Does this mean nothing? Is this a situation where rare things that are previously unreported all of a sudden get reported and are just that; rare things that are suddenly getting reported
Hughes: What did you make of the immune deficiency aspect?

Bolan: The initial definition of that immune suppression was not discussed in terms of T-cell counts; they were talked about in terms of the ratio between the helper and the suppressor cells in people with profoundly reversed helper-suppressor ratios, as I remember.

Reaction to the Name GRID

Bolan: The first name that started to circulate for this syndrome was gay-related immune deficiency, or GRID. I don't remember exactly when that came in to the discussion, but probably it was late '81, I would guess.

Hughes: What was your reaction to that term?

Bolan: I was pissed off about it. I didn't like it any better than I liked gay bowel syndrome five years earlier, that King Holmes and Larry Corey in Seattle were writing about. I just found it offensive. Had I been trained as an epidemiologist, I might have had a little bit more scholarly umbrage and said, "It's too defining and narrowing before you have any data to support that label."

Speculating on Etiology

Immune Overload

Hughes: What happened next?

Bolan: Then I think we started speculating about what could be causing immune deficiency. That's when all sorts of theories begin to
fly. And I think the article in *Time* of December 21, 1981, with Moammar Qaddafi on the cover, summarizes where we were pretty well.

**Hughes:** I have your quote from that article: "This constant, chronic stimulation to their immune system may eventually cause the system to collapse." The immune overload theory.

**Bolan:** Yes, that was a very popular theory at the time.

**Hughes:** Was that a theory that predated the epidemic?

**Bolan:** No, not that I know of. It was one of those tortured explanations that we came up with to try and understand this [syndrome], before we really knew enough about the epidemiology of the epidemic and before it became clear that it was a viral etiology.

**Hughes:** Or that it was transmissible?

**Bolan:** Transmissible, that's what I mean. I think this article is probably a pretty good summary of where people's thoughts were about this at the time. Dan William and Michael Gottlieb were quoted, and Michael, bless his heart, comes up with the most salient point. He says "both the virus and homosexuality 'have been around for thousands of years.'" Thus he concludes, 'there is a piece of the puzzle missing.'"

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**Bolan:** I suppose that I probably found myself more receptive to the notion of immune overload because of my history with STD work, and knowing what the burden of STDs in the gay community really was. I mean, I knew that for years.

### Cytomegalovirus

**Bolan:** Larry Drew did a study at the VD clinic in San Francisco, looking for CMV [cytomegalovirus], being able to grow it in the urine, and being able to detect antibodies in the blood. He determined that, I think it was, 93 percent of the gay men that attended the clinic had CMV antibodies; 70-some percent of straight men attending the VD clinic had antibodies; 40 percent of either blood donors at

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1 "Opportunistic Diseases: A Puzzling New Syndrome Afflicts Homosexual Men," p.68.
Irwin Memorial had antibodies, or pregnant women delivering. So he looked at four different population groups and found essentially that CMV is a very widely prevalent human virus, number one, but that its prevalence is multiplied by sexual activity. In the most sexually active people, that's where you find it the most.

Hughes: So that's the cofactor.

Bolan: Yes. He found that not only were sexually active gay men infected with CMV, they were more likely to be infected with multiple strains of CMV. He was only able to culture CMV from the urine, grow the virus actually from the urine, in the gay men. He was not able to grow the virus from the urine of straight men. [That finding] suggests a higher burden of virus [in gay men]. But also remember, if this was done in 1981, HIV was already in the community, already had a prevalence-- I think it was fairly high by '81; I think it was like 25 percent by '81 already. So back in '77, it was like 1 or 2 percent; '78-'79, 8, 9, 10 percent; by '81, it was already 25 percent; and by '83, it was 50 percent. Approximately. Those numbers are available somewhere.

So the point is that Drew's study findings could be confounded by the fact that HIV was already prevalent there and causing immunosuppression and causing more CMV to be excreted in the urine. At that time, we didn't know anything about HIV, of course, and so we were just looking at the CMV picture and saying, "Hey, we know that CMV is immunosuppressive. We know that from other studies that have been done." We know to this day that people who are infected with CMV may have an abnormal helper-suppressor ratio. They may have more suppressor cells than helper cells, just because they are immune suppressed from the CMV. There's a persistent percentage of sexually active gay men who are HIV-negative but still have slight degrees of immunosuppression. That's a little-acknowledged fact. The point is that there was plenty of credibility to be given to an immune overload idea.

Amyl Nitrate--"Poppers"

Hughes: Yes, I can see that. There's another theory--poppers. You were quite active on that subject.

Bolan: I was, I was on a goddamn crusade against poppers. [laughter]

Hughes: Well, talk to me about that.
Bolan: Well, very early on, the idea that poppers might be an important cofactor for Kaposi's sarcoma was something that was very actively investigated and considered.

Hughes: Why Kaposi's particularly?

Bolan: One of the early studies suggested that there might be a correlation, and then other studies failed to find the correlation. And I don't know, if we were to look at it again, whether it may be a minor cofactor. I mean, we now know that KS is caused by HIV in synergy with a newly discovered herpes virus. But is the presence of an agent like poppers going to help manifest the KS?

Nitrates are heart stimulants, and stimulants of other things. They're blood-vessel-dilating drugs. And when you take a hit of poppers, the first thing that happens is you get intense vasodilation of all of the arteries and arterioles in your head. So you get this rush of blood that goes to your brain, and it dilates your skin; you get flushed. The reason that we looked for the link was because, with the vasodilatation, whatever other cofactors might be present to bring Kaposi's out would be more likely to be carried through to the most distant part of the circulation where the capillaries end, where the trains turn around, and deposit it out there to do their evil as time goes on, with whatever else causes KS.

We went through all sorts of epidemiological questions like, Well, could it be a behavioral cofactor in that poppers are really more of an indicator of intensity of sexual activity, and number of different partners, and frequency of sexual acts, and so forth? And nothing more than that?

But anyway, during the time that we didn't know the answer to this question, spanning, oh, probably a year and a half, two years, maybe more, poppers were out there. The stuff was out there, being sold in bookstores and over the counter in gay sex shops and stuff like that, totally unregulated. The FDA didn't regulate it, because it wasn't a drug. It was a drug; of course it was a drug, but it wasn't a drug because guess what? They were filling up these little brown bottles, and calling them "locker room odorizer." The companies were very, very careful not to explicitly state what the function and the purpose of poppers were.

And that really offended me. That really pissed me off, because here are these companies making money on this shit, and not owning up to the fact that it was used for a purpose other than for which it was advertised. It was just so patently
ludicrous and obvious that if there was an iota of possibility that it could be linked with AIDS--and there was more than an iota of possibility--I was pissed off that the FDA wasn't doing anything about it. And I was pissed off that the public health department wasn't doing anything about it, so I took on this crusade to take these people to task.

Hughes: How did you go about it?

Bolan: Well, I did what I always do when I want to take somebody to task for medical things: I did an extensive literature review and got the documentation that I could put together that pointed out the various known health risks of constant exposure to poppers. I can't remember whether I requested a hearing from the [San Francisco] board of supervisors or--

Hughes: You certainly went to them.¹

Bolan: Yes, I went to them. I can't remember whether I went to them and it was something else that they were doing and I was just there with this in their face.

But what I was after and what I got eventually was a sign that was mandated by the health department to be put in a prominent place wherever the stuff was sold, stating that inhalant nitrates are potentially injurious to your health. It stated all the known possible effects—that they could cause: heart rhythm disturbances, bleeding episodes in the head, sinus infections, skin infections, and in rare cases, blood hemolysis (blood breakdown).

Hughes: But nothing about KS?

Bolan: No, because we didn't know. My principles are always, stick to the facts. If you want to make a case, you can talk about speculation in private discussions when you're trying to strong-arm somebody and lobby somebody. But when it comes to public education, you tell the truth, the whole truth, and nothing but the truth.

Hughes: And did you say just that to the city as well?

Bolan: I honest to god don't remember. That may be in some of the notes. One of the files in there almost certainly is labeled "inhalant nitrates."

¹ The Baphron [BAPHR newsletter], April 1, 1982, 2. UCSF Library has a collection of back issues of The Baphron.
Hughes: I don't see anything in my notes indicating that you made the direct link in print between poppers and KS.

Bolan: But I may have in presentation.

Hughes: You were quoted in a Chronicle article that appeared in March of 1982\(^1\) as saying, "There are great doubts in the scientific community about the safety of the use of these inhalants as anything more than occasional drugs. I would recommend that people strongly consider not using them at all until more information is known." No direct tie-in with KS.

Bolan: Right. But there may be something in my notes in those files.

Hughes: Here's another note of mine: In April of 1982, you appeared before a board of supervisors committee saying that the "poppers industry," as you called it, "should 'own up to the reality' that its products are being used as recreational drugs and should be required by law to print health warnings."\(^2\)

Bolan: Yes, I remember that verbiage. [laughs]

Hughes: Is that enough discussion about etiology?

Bolan: Is that enough? Yes, I think so.

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**Early Uses of the Term "AIDS"**

Hughes: Grmek in his history of AIDS dates the term "AIDS" to a CDC meeting in Atlanta in the summer of 1982.\(^3\) But going through The Baphron, I saw the term "acquired immune deficiency syndrome" used before that, in an issue of April 1, 1982.

Bolan: I don't have a clear recollection of when the term came into being. I remember that a consensus group was polled throughout the country for the naming of the virus, HIV, which occurred several years later.

\(^1\) March 24, 1982, p. 3.

\(^2\) The Baphron, April 1, 1982, p. 138. UCSF Library has a collection of back issues of The Baphron.

Hughes: That was in 1985.

Bolan: I don't remember any such thing for "AIDS". My guess and memory is that it came into being probably in early 1982, because "GRID" started to be used somewhere around late 1981, and it had a very short life.

Hughes: Why?

Bolan: I know exactly why: the first transfusion [AIDS] case was in December of '81.

Hughes: So there was startling proof that the "gay" was wrong.

Bolan: Yes, this is an infectious disease--sorry. Never mind immune overload.

Hughes: But that transfusion case was December of 1982.¹

Bolan: I'm sorry, you're right.

Hughes: Even the term "AIDS" goes through an evolution. An early publication of the Gay Men's Health Crisis in New York, and I think some of your documents, speak of it as AID or A.I.D.S.

Bolan: Yes, that's right.

The Kaposi's Sarcoma Clinic and Study Group, UCSF²

Hughes: What were your associations with the KS Clinic and KS Study Group, which met for the first time in September of 1981.

Bolan: My connection with that group was kind of peripheral, because it met during the day. It was a typical university kind of a thing: "Hey, we're happening. Where the hell are you? You got a life? You got a practice? What's the matter with you?" [laughter] And

¹ A few of the earliest cases of what was later recognized as AIDS occurred via blood transfusion. See, among other sources, Grmek, History of AIDS, pp. 26-27.

now that I'm part of a university, I can say that, because I do that too.¹ But I hauled myself over there to more than a few of the meetings. They were very interesting and informative, and by this time, Marcus Conant was in full swing.²

Hughes: Now, you're talking about the study group which met after the clinic. You didn't have any part in the clinic itself?

Bolan: Right. Although I think maybe once or twice, I came a little bit early and I saw a couple of patients, kind of show-and-tell type of thing. But yes, I'd come for the study group. Marcus was in his early glory, being in charge. I have the greatest respect for Marcus; he's done a lot of really good work.

Hughes: Is there a reason that Conant wasn't a member of BAPHR?

Bolan: Yes, he was closeted. Beginning and end of statement. Now, if you ask him, he will give you a different answer. He calls it "BAPHRA," always did call it "BAPHRA," but it isn't "BAPHRA," it's "BAPHR." He will say, "It is a social organization. I had no need for a social organization. They were a do-nothing group." That will be his answer. But the main answer is, I think he was closeted.

Bolan as a Link between University and Community Physicians

Hughes: Did Conant regard you as a link to the community physicians? Had you known him in any other way before that?

Bolan: I don't remember our first meeting. Did you come up with that idea independently of Gerald Oppenheimer who did the interview with me?³

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¹ At the time of the interviews, Dr. Bolan had recently taken a position at the University of Southern California School of Medicine.

² See the oral history with Marcus Conant, M.D., in the AIDS physicians series.

³ Dr. Bolan sent the interviewer an undated draft of an interview which Oppenheimer conducted with him in connection with an oral history project which he and Ronald Bayer were conducting with AIDS physicians across the United States.
Hughes: Oh, yes. There's evidence in Marcus Conant's notebooks, as he calls them—they're actually binders—documenting the epidemic as it appeared to him.¹

Let me read the memo. The first organizational meeting for what was to become the KS Clinic was held on July 9, 1981. He says that you are going to administer CDC questionnaires to patients and that he will be contacting you "to assist in developing a psychosexual history on these patients."² So somehow, he knows your past work experience.

Bolan: What that means is probably he was aware of my visibility at BAPHR regarding scientific issues and the meeting that I put together in June of 1980.

Hughes: How, if he didn't have strong links with BAPHR?

Bolan: Well, it was a big deal; it was a big meeting. Marcus could have become aware of me through that. My guess is that he was doing some surveillance of what BAPHR was doing and came to learn about me that way. Maybe he was subscribing to The BAPHRON, for all I know.

Hughes: There's no sign of it in the notebooks.

A Conversation with Jim Curran, May 1981

Bolan: Interesting. Another possibility is, I had a discussion with Jim Curran from the CDC in probably June, right after the MMWR article.

Hughes: Curran was at the San Diego meeting in late May.

Bolan: Of course. Yes, I knew Jim back then.

Hughes: Is that how the meeting learned of the PCP cases?

¹ Conant has since donated his "notebooks" to the AIDS History Project at UCSF Library.

Bolan: Yes, because he brought the information. That's probably right. I'll bet you that is where I first heard about it, if he was at that meeting. I'll bet you, that's right.

Hughes: Well, I have notes which I just now discovered. The meeting that we're talking about occurred on May 30, 1981, in San Diego. I don't know the formal title, but it was an annual CDC conference on sexually transmitted diseases.

Bolan: Exactly.

Hughes: Curran announced five PCP cases which would appear in the MMWR the next week.¹

Bolan: So I'm right, that is where I first heard about it.

Hughes: I got the following information from Paul O'Malley, who was also at that meeting.² He went to an informal meeting in David Ostrow's room that night with Jaffe, Curran, and a few gay M.D.'s. He couldn't or didn't tell me their names. Were you possibly one of them? Do you remember going to David Ostrow's room?

Bolan: I don't remember that meeting. It would have been logical for me to be there.

Hughes: From Paul again: there was already talk of two possible causes, poppers and an infectious agent.

Bolan: Anyway, Jim did call me a couple of weeks later--I don't remember exactly when Jim called me. But if Marcus's memo is dated--what was that?

Hughes: July 7.

Bolan: So Jim must have called me between when we got back to San Francisco from that San Diego meeting and that date. So he talked to me some time in June, because I said that I would be glad to be part of a case-control study.

Hughes: Oh, did you?

Bolan: Yes. I participated in that first case-control study. I supplied patients from my practice.

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² See the oral history with Paul O'Malley in this series.
Hughes: Did he know about the KS cases at that point?

Bolan: I don't remember whether he knew about KS. I've got a feeling that maybe I wasn't at that meeting in Ostrow's room, because I remember what Curran was asking me was, "What's going on out there? What are you seeing?" He would have asked me the same questions in Ostrow's room, so I probably wasn't at Ostrow's meeting. I remember that question very clearly, and I told him about the lymphadenopathy, which was all that I had seen at this point.

Hughes: I think both MMWRs mentioned lymphadenopathy.

Bolan: Yes. We talked for about ten minutes, fifteen minutes, something like that. He said, "Okay, thanks." [laughs]

Hughes: And that was the end of that?

Bolan: "Next." That was the end of that conversation.

More on Bolan as a Link between Physician Groups

Hughes: One more reference to Conant in this very early period. Conant periodically sent memos to the group interested in these new cases of KS. Were you on that circuit?

Bolan: I think so.

Hughes: The memos announced the date and time of the next meeting, and usually the speaker. They were quite brief, a paragraph or two.

Bolan: Yes, I do remember.

Hughes: Anyway, this is one of those memos, and he said, "At our last meeting, we began the discussion of the type of advice which should be given to patients suffering from Kaposi's sarcoma--regarding their sexual activities and things that they can do to improve their immune system. We would like to continue this discussion with Dr. Robert Bolan and other physicians from the community, and extend the discussion to the significance of the Helper-Suppressor studies in apparently healthy gay men."1

1 Conant memo to Kaposi Sarcoma Study Group, October 5, 1982 (John Greenspan personal papers, 89-0117, box 2, folder: Conant, M.A.: JG/Beckstead etc. 1982).
Bolan: Well, there's ample evidence, that I had forgotten, that he did obviously see me as a liaison.

Hughes: Conant has university affiliations, of course, strong ones. But he's also got a very active private dermatology practice. So why doesn't he have his own ties to the community? Why--to put it bluntly--does he need you?

Bolan: [laughs] Well, I guess most likely because he had a university practice, his office was at 350 Parnassus Avenue.1 So his universe was across the street, back and forth across the street. UCSF is and was a notoriously conservative place where you just didn't come out in any way, shape, or form. So I think that he was isolated. And I came to his attention by whatever means, either through the STD work, or that he was monitoring BAPHR because he knew that it was a group that was paying attention to what was going on, and when he looked into it, however he did that, found that I was the guy with the biggest mouth. [laughter]

Hughes: Did you function as a liaison?

Bolan: Well, I didn't do it intentionally; I never really considered myself as serving that function for him.

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Bolan as Head of the Kaposi's Sarcoma Research and Education Foundation

Bolan: Now, when he asked me to chair the KS Foundation in January of '83--

Hughes: It was formed in April of 1982.

Bolan: He asked me in January of '83. I remember he took me to dinner at Neiman-Marcus. Neiman-Marcus had a restaurant with tiered seats; it was right after it was opened. But I took over the reins of the foundation in June of '83.

Hughes: Again, why you?

Bolan: Well, because I already had this relationship with him.

Hughes: Why didn't he do it? You had a practice too.

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1 Conant's dermatology practice office is adjacent to the UCSF campus.
Bolan: Right. I never asked that question. Oh, I know why me. It's not mysterious. The reason was, he'd been the president of the KS Foundation, but he had greater ambitions. He wanted there to be a national KS foundation with chapters. So he wanted to turn over the leadership of the local organization to someone else, so he could focus on the national. That was the reason that he asked me. Now, the "why me" is I think because I continued to be the most outspoken; I wasn't the most medically informed. I always looked at Bill Owen\(^1\) as being the smartest kid in our class.

Hughes: In general, or in terms of knowledge about the disease?

Bolan: Oh, just knowledge about medicine. I always looked up to Bill as being a very knowledgeable physician. Something went in, it just never came out again. It just stayed in there, and it got integrated. [laughter] Good doc.

**Bolan as Activist**

Hughes: What I'm getting at--I've actually seen this in the documents too--is that at least at this early stage, would you say that you're serving as BAPHR's spokesperson, spokesman--can we use that sexist term?

Bolan: Sure, I think we can use that sexist term. [laughter]

Hughes: Would you go so far as to say you were the spokesman for the gay community? I guess that's too grandiose.

Bolan: Much too grandiose.

Hughes: Yes, there were many. But for gay community physicians?

Bolan: I don't think so. I was a serious-minded person with a real commitment to careful scholarship, researching what I did before I made any pronouncements. Not to say that I didn't make tons of mistakes and had stupid leaps of faith and stuff like that. But I tried to be that.

Secondly, I wasn't bashful or afraid to stand up in front of a group of people and speak my mind. I was pretty good at convincing people of a viewpoint that I held strongly. So I guess it was a combination of the care and attention to the scientific

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\(^1\) See William Owen's oral history in this series.
inquiry and a willingness to be a mouthpiece. At one point, I considered myself a media queen.

Hughes: Did you like that role?

Bolan: For a very short time, I did. It got old real fast. It's real wearing to be a media queen. Marcus has never tired of it. [laughter] I just heard him on Terry Gross on "Fresh Air." She interviewed him a few years ago, and she just interviewed him again right after the Vancouver conference [International Conference on AIDS]. It was really an excellent interview. I mean, the man is brilliant. He's an excellent speaker, an excellent lecturer. But he's a media queen. [laughs] That's all right.

Hughes: And Dr. Bolan has retired from that role.

Bolan: Yes, but you know what? I'm having my second wind now.

Hughes: On what subject?

Bolan: The position that I have kind of retired myself into as medical director of the Gay and Lesbian Services Center in our fair city of Los Angeles. We'll talk about that when we come around to the end, but I've kind of come back to my roots, my community-based activist roots. I'm finding that those juices are still flowing and I can still get pissed off about things. I can see a few podiums that I'm going to stand behind yet. And it's fun and exciting.

So I think that's why Marcus looked to me--because I had leadership qualities. I was the most obvious choice, I guess.

A National Meeting On AIDS, New York City, Winter 1983

Bolan: I didn't even find out that Marcus was gay until he obliquely came out to me when we were coming back from god-knows-where on a plane. In fact, I think it was that meeting that I went to in New York in December of '83. That was the first sort of national meeting on AIDS, in New York, in the winter; it was colder than stink. And I'm sure that it was November or December of '83, or

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1 Terry Gross is the interviewer for the National Public Radio program, Fresh Air.
something like that. I remember the ballroom. I would guess that
there were somewhere between 80 and 150 people there.

I remember remarking to Marcus in the foyer that here we
were, this relatively small group of people, that were the
nation's informed experts. Very naive at the time, very primitive
at the time, but this disease was something very, very important,
and here we were. It was really the first memory that I have of
reflecting upon the national impact of the epidemic, being in the
middle of a national thing. Not that I didn't have understanding
of the national significance of it before then; I certainly did.
But me as part of that.

Hughes: Was Conant at that point focused on the KS part of the syndrome?

Bolan: Yes, I think so.

Let me give you this one little piece, and then we'll go on.
What Marcus said to me is, "We've got to find the answer to this
so Marcus can go back to the bathhouses." It's the funniest damn
thing.

Bolan's First Cases Of AIDS

Symptoms

Bolan: Anyway, my first case of AIDS in my practice was a man with KS,
not with an opportunistic infection.

Hughes: When was that?

Bolan: That was in early '82. See, I had a very young practice at this
point. I didn't have a burgeoning practice, because I just came
to San Francisco in 1979. It took about five or six years to
develop a good, robust practice in San Francisco. I was probably
one of the last generalists to come to town and hang out a shingle
and make a practice go.

Hughes: Were you hoping for a gay practice?

Bolan: I wanted largely, mostly a gay practice.

Hughes: And is that what you had at that point?
Bolan: Yes. I had a lot of people in 1980 and '81 that had very peculiar illnesses that I couldn't explain—fevers and night sweats and lymph node enlargements and very bizarre neurological presentations. I had no idea that those were really part of this big, massive epidemic. But while I had patients that had something manifested, the vast majority of my patients who were infected were still incubating, if you will. They were infected but clinically well. So my patient population began to mature, if you will. I can't remember what month it was, but I think it was about April or so of '82.

Hughes: Meaning by "mature", to exhibit symptoms that you could then classify as part of this syndrome?

Bolan: Yes. Declare themselves with this diagnosis.

Hughes: Had they complained of something, or were they coming just for regular checkups?

Bolan: Fortunately, I have all these medical records. I don't have them here; they're archived in San Francisco, but they're going to stay there in my practice. [beeper interruption]

The complaints that stand out in my memory are the really unusual things, the really strong clinical syndromes—the fevers and the night sweats and the lymphadenopathy and the bizarre neurological presentations with paralysis and bizarre pain syndromes. The more subtle symptoms of fatigue, intermittent diarrhea—the full spectrum of HIV symptomatology—I don't really remember very well. I know that it must have been there.

Lymphadenopathy

Hughes: Were swollen lymph nodes a common symptom?

Bolan: That was pretty obvious as a very early manifestation of HIV infection. I think—in fact, I know—that the number of people with HIV who presented with clinically significant lymphadenopathy was much greater in the earlier years of the epidemic than subsequent years.

Hughes: Why?

Bolan: I think the answer is probably multifactorial. I'm sure that other epidemiologists and clinicians have thought about this and have probably written about it, for all I know. One of the
reasons is obviously treatment. Since 1986, we've been treating people, and that has some effect on the virus in the lymph nodes. Another possibility is that many of the people who were infected early in the epidemic went from infection to death in a very short period of time. I don't know whether those people were more immunosuppressed when they came to their HIV infection, i.e., with multiple infections with CMV, making them a more fragile host. Probably that's part of it.

But for whatever reason, lymphadenopathy was a very prominent thing. I'm not talking about tiny lymph nodes [as] when you get a sore throat; we're talking about big, giant lymph nodes that you can see from looking at the person across a crowded room. And when you feel in their armpits, there's a two- and three-centimeter and sometimes four-centimeter in diameter knotted group of nodes. It wasn't a subtle thing. And usually associated with that lymphadenopathy was this fever and night sweat. What we know now is that many of those people were going through their initial infection.

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Bolan: Early in infection the virus becomes sequestered or stored in lymph nodes. Unless the immune system is able to contain or suppress the virus, then the lymph nodes become these little virus factories. I don't know whether the people that had this more prominent syndrome had more virulent infections or whatever.

Terms for Pre-AIDS Status

Hughes: Donald Abrams used the term "pre-AIDS" before the term ARC [AIDS Related Complex] was coined.1 And then there was also AIDS prodrome. Now, are those synonymous terms?

Bolan: Those are all synonymous. And I think that pre-AIDS was the first term.

Hughes: Yes, I think you're right.

Bolan: AIDS prodrome may have been contemporaneous with that, or it may have been slightly later, but ARC was definitely the final resting place for that "not-quite-AIDS" group. It was probably one of the

1 For more on the concept of pre-AIDS, see the oral history with Donald Abrams, M.D., in the AIDS physicians series.
first terms that had political input from the HIV-infected community, because to have a diagnosis of AIDS was not only a stigma, but it was considered a death sentence. ARC was defined as a group of symptoms or syndromes that were part of the same spectrum but weren't as profound an immune suppression or immune damage as AIDS. It was obviously preferable for people who had something that was part of this spectrum, but not AIDS, to have a special category that didn't stigmatize them as much and didn't give them a death sentence.

So the idea was to define titles or stages, calling it AIDS stage I, stage II, stage III. Discussions were held around the country about, Now that we understand that there's a spectrum of this disease, what do we call the different categories? Because if you were going to call it stage I, stage II, stage III, it would carry an onus with it that we didn't want to have.

Hughes: The idea was to split the disease into stages but without implying that there was a progression?

Bolan: Exactly. And frankly, we didn't know what the progression rate was at this point.

Hughes: Did you label patients ARC?

Bolan: Yes, I have a lot of medical records in which I put ARC.

Hughes: What did you mean by the term?

Bolan: AIDS Related Complex meant a group or "complex" of signs or symptoms that fell somewhere on the spectrum of AIDS but less severely than "full blown AIDS." I can't remember exactly when the term came into use.

Hughes: I think it's 1983, but I'm not sure.

Bolan: Well, if it's before 1985--

Hughes: Oh, I'm pretty sure it is, because by then you've got the antibody test.

Bolan: But that doesn't tell you the natural history of the disease. See, AIDS is a clinical diagnosis. HIV-positive is a serological diagnosis. ARC, pre-AIDS--those are all clinical diagnoses. But if it was '83, then none of us really had enough patients that we had followed for a long enough time to know that there was an inevitability that patients would progress to AIDS. But by '85 and '86, I think it was pretty clear. In fact, Andrew Moss came out with predictions which were published.
Hughes: The AIDS incidence study that was published in 1983?
Bolan: Is that the population-based study?
Hughes: Yes.
Bolan: The ZIP-code based?
Hughes: Yes.
Bolan: Yes, that's the case clustering study. That was '83?
Hughes: That was published in '83 in *Lancet*.
Bolan: Then it was after that, because this next study was a case-cohort or longitudinal study that showed progression in a short period of time. Moss made a prediction that if this rate of progression over the period that he'd observed it, from ARC to AIDS, holds true for the whole cohort, then greater than 90 percent of people with ARC will eventually have AIDS. That was the first objective or scientific analysis that I'm aware of that came to that conclusion. I think it was '84.

**Physicians' Hope and Denial**

Bolan: Then we had '84 to '86 to live through before we had AZT, where we knew that even ARC was a death sentence. What's amazing is the power of hope and denial. Hope and denial are sometimes opposite sides of the same coin. Those of us who were practicing physicians--I probably should only speak for myself, but I think I can be a little bit inclusive of some of my colleagues--we wanted to hope for the best, and we didn't want to see all of our patients die or think that all of our patients were going to die. So we engaged, I think, in a little bit of hopeful denial of what seemed to be the reality.

It was only the scientists--like Andrew Moss, who was sitting in his office, crunching numbers and doing his epidemiological predictions--that were the doomsayers. We didn't like to see Andrew come to meetings, because he always brought bad news. But he was very helpful and very intellectually alive.

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Hughes: I think he was feeling it too. He told me that when his study appeared in *Lancet*, he took off for London because he couldn't face the consequences of what his study meant for the gay community.¹

Bolan: I had no idea that he did that. What popped into my head as you were talking is a conversation that I had with Andrew when he was presenting his predictions to me and one other person before they were published. I remember the look on his face and the horror in his voice. He was profoundly moved by the implications of his data. And I didn't remember that until just now.

Earliest Phase of the San Francisco AIDS Epidemic

[Interview 2: August 14, 1996] ##

The CDC Case-Control Study, 1981

Hughes: Dr. Bolan, we mentioned the questionnaire for the CDC case-control study. Did you indeed get involved?

Bolan: I was definitely involved with it, but on looking at this document in my records, [reads quickly] "Kaposi's sarcoma and *Pneumocystis* pneumonia in homosexual men, a case-control study," I know for sure that I never administered this questionnaire to anybody, because this is extremely detailed, and I know that in my entire life, I've never asked this many questions of this personal nature of anybody.

But I have a number of notes throughout this document, which indicates that it was given to me to make comments on, and that this was probably a working document, even though it doesn't say "draft" or anything like that on it; since it doesn't have a date, that's what I'm assuming it is.

What I remember is the phone call that I had with Jim Curran—I probably had a couple of phone calls with Jim Curran—in mid-June [1981] right after the San Diego meeting. He asked me what was going on in San Francisco, and then I probably had a subsequent conversation where we talked about a case-control study. Maybe it was the same conversation, I don't know. But I

¹ See the oral history with Andrew Moss, M.D., in the AIDS physicians series.
remember agreeing to participate in the case-control study, which meant that I would help to formulate the questions and I would identify as many patients from my practice that could be either cases or controls. That's what my participation was.

Hughes: Conant noted that you would help in developing a psychosocial history. Was that where he wanted your input?

Bolan: Yes. And I think there's a place in here where--[looks through questionnaire] Well, there's one section where they ask about medical illnesses, and then I have about five or six or seven additional suggestions down here that they hadn't included, like gonococcal proctitis, lymphogranulonum venereum, granuloma inguinale, some uncommon STDs, but things that were definitely seen in the population. And I added a couple of popular street drugs to the drug history. They had, "Homosexuality will be defined as having had sexual intercourse with a man." Then I indicated some expansions of that, "What do you mean by sexual intercourse? What kinds of sexual activities?"

Hughes: Do you know who administered this questionnaire? Was this a CDC effort?

Bolan: As far as I remember. They probably deputized people in the public health department, like Paul O'Malley. He might have even been involved, and if you have an opportunity to talk to him again, you might ask him that. That's typically how the CDC would work in collaboration with local health departments on matters like this.

Hughes: The CDC did send people to San Francisco; Mary Guinan and others were in San Francisco in the very early period of the epidemic. But they didn't stay, did they?

Bolan: Right.

Hughes: They didn't stay long enough to administer an exhaustive questionnaire like this?

Bolan: I don't remember at what point people from the CDC came and stayed. I do remember George Rutherford. He was an employee of the CDC, and he was later at the San Francisco health department for a long time. But he was there later, like '85.

Hughes: I'm thinking of the early stages of the epidemic.

Bolan: But there was somebody that preceded him, and there may have been folks that were there intermittently. But that's the best I can do.
Hughes: I remember two things about the CDC study. The conclusion was that it was number of partners that was the risk factor—the lifestyle hypothesis. The second thing is that the controls were mainly or exclusively from the VD clinic in San Francisco, many of whom, it was later realized, were probably already HIV-infected.

Bolan: Actually, I think they had a couple of different cohorts, because I remember that for the participants from my practice, and I don't remember how many patients I enrolled, they wanted as case-controls neighborhood controls, men living in the same neighborhood as my patients. So the definition between a case and not a case was the seeking of medical attention. I'm sure that they did pick up some from the VD clinics. Probably, they would have tried to use neighborhood controls for them too, because that was the finest distillation I think that you could make on this.

An Early AIDS Pamphlet, December 1981

Hughes: [tape interruption] A pamphlet¹ which is probably one of the earliest pieces of AIDS literature, before the outbreak was even known as AIDS, was circulated in December of 1981, and I think you had a hand in it. It was on KS.

Bolan: It had a picture of a lesion on it?

Hughes: Yes. There were several, as a matter of fact.

Bolan: Yes, there were about three pictures. They were color photos.

Hughes: I know from talking with Jim Groundwater² that the pictures were of Ken Horne, or at least the picture of the lesion in the mouth was of Ken Horne.

Bolan: Ah, yes, that's right.

¹ "Disseminated Kaposi's Sarcoma in Young Homosexual Men." The pamphlet is not dated but a note from Conant states that he hopes to have it published by December 4, 1981. (Conant to Bolan, December 1, 1981. Conant notebook #1, UCSF Library.) A copy of the brochure is in the appendix.

² See the oral history with James Groundwater, M.D., in this series.
Hughes: They were distributed in San Francisco, and also 3,000 were sent to New York to Alvin Friedman-Kien, and 3,000 to BAPHR. Do you remember any of this?

Bolan: I clearly remember the brochure, and you might find a copy of it in here. [points to the three cartons of his documents]

Hughes: I haven't yet.

Bolan: That's too bad, because I wanted to try to keep a couple of them, because they were very good photo reproductions. Who put that out?

Hughes: Marcus Conant, Jim Groundwater, and Alvin Friedman-Kien prepared it. BAPHR undertook distribution in San Francisco.

Bolan: That's right. BAPHR didn't pay for the brochure; BAPHR undertook the distribution.

Hughes: Yes. There was funding from a couple of private sources.¹

Bolan: Yes, that's what I remember. I think my involvement with that was merely to help with the distribution of it, the announcement, "Here it is; here's a useful brochure." But I didn't have a hand in the writing of it.

Relative Predominance of Kaposi's Sarcoma and Pneumocystis in the Early San Francisco Epidemic

Hughes: Do you think it's indicative that while PCP and maybe other opportunistic infections were mentioned in passing, the brochure is really about KS?

Bolan: Oh, absolutely.

Hughes: Why the emphasis on KS?

Bolan: It was probably because KS was the most prevalent of the early diseases associated with the new syndrome in San Francisco. You could check that against the known public health figures and stats and stuff like that. But even if it wasn't the most common manifestation, it was the most obvious and visible sign that

¹ According to the brochure, funding was provided by the Neutrogena Corporation and Barnes-Hind Pharmaceuticals.
someone had this condition. In the very early stage of the epidemic, we certainly didn't understand what the relationship between KS and PCP was. And if memory serves me correctly, I think there was a typical medical attempt to group things into different categories rather than to lump them. Before you know that you can lump, you group. That's probably a historian's principle, too.

Hughes: Yes. [laughter]

Bolan: It's a good scientific principle.

Hughes: Meaning that if you diagnose a cancer, you classify it as a cancer; if you diagnose an infectious disease, you classify it as an infectious disease.

Bolan: Exactly.

Hughes: Unless there's a good reason to link them.

Bolan: Yes. I think the appearance of KS as a distinct objective thing or manifestation of an illness that was so frightening, the occurrence of that phenomenon brought out a couple of really strong physicians, Alvin Friedman-Kien and Marcus Conant. This was a disease in their specialty.

Hughes: Yes, dermatologists initiated the brochure.

Bolan: Exactly. It probably could be stated that in the early months, if not year or so, it was a dermatological phenomenon.

Hughes: Not dermatological/oncological?

Bolan: Yes, it was dermatological/oncological. But there are other kinds of conditions, like mycosis fungoides, for example, which is a cutaneous lymphoma which dermatologists will treat. They will treat superficial skin cancers. So there's some overlap between the two specialties. So I think that it's primarily because of those factors that I mentioned.

Hughes: Could early PCP symptoms be diagnosed and dismissed as a cold? Something not as frightening as a purple lesion?

Bolan: Yes, I think you hit upon it. There's no escaping the certainty of a purple lesion. That's a clear message. Fevers and night sweats and cough that come and go are not as frightening, because at that point, nobody knows the full flower of the plant. When PCP came, it came with a vengeance, but it was an infectious disease that we could get people over and we could cure, but in
pre-1985-'86, they weren't routinely providing prophylaxis. So people would get sick in episodes. But they would recover from the initial one.

Hughes: An average physician would be able to diagnose PCP?

Bolan: At that point, probably very few physicians would be able to diagnose it at an early stage. But in San Francisco, anyway, it probably didn't take very long for the physicians who were caring for the at-risk population, who are all pretty tightly networked together anyway, it didn't take but weeks before the word got through the provider community that a severe pneumonia with high fevers and a certain pattern on an X-ray, we had a new differential diagnosis to consider here.

Hughes: So you can readily distinguish PCP by X-ray.

Bolan: Well, it has a characteristic pattern, but there can be variations from that pattern that are atypical, and there can be people that have normal chest X-rays in the very earliest stages [of PCP]. So it can be very tricky sometimes. But would the generalist physician in San Francisco who maybe had one or two gay men in his practice, and maybe didn't even know that he had one or two gay men in his practice, would he be likely to pick this up in late 1981? Probably not.

Hughes: So for several reasons, PCP could slip into the woodwork, so to speak, where KS--

Bolan: Yes, where KS was an absolute sign, an unquestionable sign of the new syndrome.

Hughes: How do physicians come to accept something or -things as a syndrome?

Bolan: That's a very good question. I've thought a good deal about that over the years. I haven't gone out of my way to find whether or not people have written about this, but I have come across it.

I remember being perplexed by things that I hadn't seen before, and in the very early days, before I had a place to categorize them and a place to put them, I would sometimes discount their importance, particularly if it was a spoken symptom that had no objective findings associated with it. I would say, "I don't understand what that means. That doesn't correspond with anything that I know," and dismiss it.

Over the years, I have observed several physicians do that. Not with regard to HIV, but with regard to a lot of things. Even
with common medical problems. And I believe it's a phenomenon that those of us who were present in the early days of the epidemic--[beeper, tape interruption] I remember that those of us who were present at the beginning of the unfolding of this peculiar syndrome with all of its mysterious and new manifestations went through various kinds of learning curves.

**Practicing AIDS Medicine**

**An Open-ended Diagnostic Approach**

Bolan: I think that one of the things that AIDS docs have learned to do is to take a history in a much more open and receptive way than we used to. If you ask a person to describe what they're feeling or to describe their illness or a set of symptoms, and they go ahead and describe them as best they can, if you don't understand what they're trying to tell you and, with further probing questions, you can't refine it to a kernel of information that you can understand, then you conclude that they're trying to tell you something that you don't know.

Hughes: Rather than dismiss it?

Bolan: Rather than dismiss it. So you say to yourself, "I don't know what that means, but I'm going to put that in a special place where I don't lose it."

Hughes: So the structure is very open, where before maybe there were neat little boxes that you put people in.

Bolan: Yes, exactly. This was the first time that there was a new disease in modern medicine times. Look back to the turn of the century as the time of the birth of the current medical methodology for taking histories and doing physical exams and making diagnoses and that sort of thing, the deductive reasoning type of thing. Something that I'm trying to teach my students and interns and residents as they come along is, "I want you to be very careful historians, and I want you to ask very probing questions and try to fit what the person is telling you into what structure you know defines diseases and syndromes. But if you get something that consistently doesn't fit, don't discard it. Put it in an 'I don't know' box, an 'I don't know yet' box."

The one memory that I have that really makes this point for me is of a young man who was trying to describe a painful
peripheral neuropathy of his feet, and this was before any of the
drugs that produce peripheral neuropathy--painful burning aching
discomfort in the feet. He was describing these very unusual
types of pains in his feet. They didn't seem to be in the joints;
they didn't seem to be on the skin; they were very difficult to
localize and very difficult for him to describe. And I didn't
know what the hell he was talking about. I began thinking that
this was drug-seeking behavior; jumping to all kinds of
conclusions. So since then, I have been humbled by my lack of
knowledge about these things.

Later Appearance of Neurological Aspects

Hughes: The neurological aspects of AIDS manifested themselves somewhat
later than KS and opportunistic infections.

Bolan: That's right.

Hughes: Why would that be?

Bolan: Well, actually, there are a couple of different times in the
course of the disease when neurological problems can occur. For
some people, they can get neurological symptoms relatively early,
like the viral meningitis from HIV. That can be a relatively
evolved phenomenon when T cells are relatively high. Some people
can get certain types of peripheral neuropathy when the T cells
are relatively high. By relatively high, I mean over about 150 or
200/cc or so.

But then the really disabling kinds of neurological problems
occur later, toward the end of the disease, when there's less
immunological protection of the central nervous system. It's sort
of like the last bastion of protection--protect the computer. And
when that breaks down, then you get the end-of-disease
neurological events. The ones that occur early seem to be largely
immune-mediated in the body's attempt to fight against the virus
and the consequences. The chemicals that it releases, the cells
that it releases which go out and do battle with the virus, cross-
react with a lot of neurological tissue, and you get early
neurologic diseases as a result of the immunologic war.

Hughes: Those symptoms were seen in the earliest cases of AIDS?

Bolan: Oh, yes. As I recall, organ-specific syndromes were defined
slowly over several years as cases accumulated and physicians'
awareness of them and their understanding of their relationship to
AIDS increased. Obviously, cutaneous was the first, pulmonary disease with the pneumonias was second, brain lesions like toxoplasmosis were third. I can't remember what was fourth and fifth, probably GI, gastrointestinal, was fourth. But neurological understanding came along a bit later. It probably wasn't until '83 or '84 before there were really scholarly descriptions of the full spectrum of neurologic manifestations of HIV disease.

Hughes: Even though people had been seeing them.

Bolan: Exactly. But nobody had been able to really put it all together. I may be off the timing by a little bit, but I'm right about the order and the procession, that the awareness of the spectrum of neurologic problems was not present early on. Some might even argue that it wasn't until the early nineties that we had the real--I hesitate to say final--understanding of HIV, because I don't think we ever will always know when a condition may have some relationship to HIV. But a much more complete understanding that we look to today didn't happen until probably 1992.

Hughes: What were you thinking as condition after condition was discovered and linked? Was that depressing in itself?

Bolan: Oh, yes. I had patient who was a psychiatrist who was sick pretty early on, and I think he lived until probably '85, maybe early '86. He died of basically an AIDS dementia. But he had a really relentless neurological disease starting with peripheral neuropathy that was initially painful, and then went to numbness, and then went to motor weakness, and just kind of slowly ascended until he wasn't able to walk any more. He became slowly demented, lost bowel and bladder control.

At one point, while he was still working, he came in to see me. He was in a wheelchair by this time, and he had pajama tops on under his shirt. I asked him about it and he sort of laughed and said, "Oh well, sometimes I take short cuts to make things easier." Eventually I realized that this response of his was part of his dementive disease. He had a peculiar disconnect between what he thought the significance of something was and what most people would think. La belle indifférence is what he had.

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Bolan: That's an old neurological term meant to describe people that have frontal lobe disease, where the higher intellectual functions are lost. They really lose their personality; they lose the sharpness of their affect. They can look at something that's terribly wrong
with them, like a big laceration on their hand, and say, "Look at that. That's funny." Not seeming to have any connection with it.

Hughes: It's not even me.

Bolan: Yes, it's not even me. But at some point when Patrick was already a bit into that process, he looked at me one day and he said, "This is a really funny disease. It's like this monster inside of me, just squirming around, trying to get everyplace." That sat me back in my chair a few inches.

Bolan's Coping Strategy

Hughes: How were you dealing with this? How did you react as a physician and how did you react as a person?

Bolan: Well, you ask: with each new horrifying manifestation befalling someone else, was there a sense of, My god, is there no end to this? Absolutely there was that reaction. It felt like an unfolding horror show that just was relentless. My reaction was to work harder, to get more involved in the AIDS Foundation and in BAPHR, and I was profoundly sad all of the time.

As a physician, when you deal with people with incurable diseases, after a while, if you're to continue to be able to do that, you develop a certain protective shell that protects you from the overwhelming sadness of what's happening to your patients. For some people, that shell manifests itself as a cool, distant attitude. It wasn't that with me, it wasn't a cool and distant attitude. The shell was a lot closer to me than far out from me. I to this day don't really know how I emotionally protected myself, except that I had a good relationship, and we were unscathed personally. And I was doing the best I could to work with these organizations to do something positive; if I couldn't do something positive in the office or in a hospital, then I could do something positive in another venue.

I guess the final thing that I did was to develop my bicycling interest as a real relief valve. I became a really obsessed bicyclist. I told this to Randy Shilts when he interviewed me in probably '85 or '84, whenever he was interviewing for *The Band Played On*, that at that point, my bicycling--I mean, I knew what the bicycling was all about. It was an attempt to be powerful and strong in a way that I didn't feel powerful in other professional aspects of my life.
Hughes: Maybe also to ride away from it for a time, too.

Bolan: Yes, sure, to escape it. I would ride up to the top of Mount Tamalpais or up into the Marin headlands, and I would find a vantage point, and I would just sit and look back at the city. Somehow, looking at the battlefield from afar, somehow gave me a perspective, physical distance, that I can't really describe. And it was also rejuvenating and renewing, because it's such a beautiful city; to be able to look at the place in which all these terrible things are happening and to be able to say, "This is a beautiful place."

Also reassuring was the comradeship with all the rest of my colleagues that were working alongside me. I think there's a lot that is reassuring and motivating and rejuvenating about comradeship in a unified cause. Everybody's hurting in the same way, so it takes a little bit of personal sting out of it.

Hughes: You had chosen a specialty [family medicine] which normally doesn't have to deal with death and dying.

Bolan: That's absolutely true, and I chose it for two reasons. One, because my interests in medicine were broad. When I was going through medical school, I became kind of bored after I had encompassed the basics of a specialty rotation, and I thought, I couldn't do this for the rest of my life. So my interests were very broad. And the second thing was that after I did my oncology rotation, I decided I didn't want to do oncology. If anything, I wanted to do infectious disease if I was going to specialize, because I wanted to cure people, and I didn't want to be a surgeon, because I didn't want to keep surgeons' hours.

Hughes: Was that all? What about the element of death in oncology?

Bolan: Well, yes. I mean, that was specifically why I didn't want to go into that, because you couldn't make people well. People died all the time. So I found myself, as a colleague of mine put it so succinctly, sitting on the tracks, playing cards, drinking beer, and the train came, and I found myself worse off than an oncologist. Because it turns out that oncologists can save some people; some people survive cancer. So for many years, I found myself being drawn more and more into this area in medicine where nobody survived, or it didn't seem like it, anyway.

Hughes: Not only didn't survive, but they were people with whom I presume you could really identify.

Bolan: Oh, yes.
Hughes: They were mostly your age, your sexual orientation. They were your people, so to speak.

Bolan: That's right. It was my community.

Hughes: Which is another difference from oncology, in which the patients are usually young or old, aren't they?

Bolan: That's true. There also was for us early physicians, for those of us who were gay men, this was family. It was worse than just same-age peers; this was family. But somewhere along the way, I learned some important lessons about what it really means to be a physician and where the real rewards are. And what I learned was that it's nice to save somebody's life from some disastrous problem and make them well, but in reality, the number of times that any physician in their career can do that is relatively limited.

Helping Patients Cope

Bolan: What we do is we help people strategize with chronic ailments. We try to help ameliorate some suffering. What doctoring is really all about is cure when you can, but relieve suffering always. It was that understanding as it gradually dawned upon me that really made me see how rich this experience was for me as a physician, to take someone who has been having unrelenting fevers and night sweats for six weeks and abdominal pain and vomiting and diarrhea, and not cure them of the problem, but diagnose what the main trouble is and treat it to relieve the majority of these symptoms.

If you take somebody who's having diarrhea of unknown cause, you work up the case and you don't find a cause, you can't cure it, if you're able to take a person who's having fifteen or twenty stools a day and treat them so that they're only having two or three or four or five stools a day, you've made a tremendous improvement in that person's quality of life. So alleviating suffering, and also giving comfort, giving hope, helping people access their own strategies for dealing with fear of the unknown, fear of death, helping people to access those coping strategies is really where the reward is. That's where the big payoff is.

Hughes: That strategy you consider to be absolutely essential to your practice?

Bolan: Absolutely, absolutely.
Hughes: Had you had any experience in doing medicine that way before?
Bolan: No.
Hughes: How did you learn how to do it?
Bolan: I just learned it, one by one, patient by patient. And oncologists take this approach. Most caring physicians have an understanding of what I'm talking about and know how to do it.

Faculty Member, University of Southern California, 1996-present

Teaching Medical Students

Hughes: Do you think it's something that can be learned?
Bolan: I'm trying to determine that right now. That's one of the reasons that I allowed myself to be recruited to come to USC and to become a little bit more academically oriented than I have been before, to see whether I can teach some of these things that I so strongly believe in and see as really central parts of being a physician. I'm not the first person to be able to enunciate these things by any means, but I've learned them by the seat of my pants. Nobody taught me about this, and I'm going to see if I can see how good I can do this.

Hughes: How so far have students responded?
Bolan: Well, I just finished my first year with two semesters of six first-year medical students. We met once a week for a half-day session, and sometimes we would meet a second time in that week for another half-day session. I took them around to various kinds of clinical venues. Some of them were AIDS-related and some of them were general medicine. And I just talked to them like I'm talking to you, telling them what my experiences have been and how to listen to people when they talk to you, how to respect them and not see them as less of a person because they've got a disease. I got rave reviews from them. They liked my approach.

My first session with them, I thought, I've never done this before; I don't know what the hell I'm doing. Nobody told me how to teach first-year medical students introduction to clinical medicine. There wasn't very much of a structure at USC, how to do this.
I've kept this file of patient memorabilia over the years. A lot of it are death announcements and letters from mothers and sisters and lovers of patients that I've taken care of, things like that. I haven't consistently kept it. The file's about three, four inches thick. I went through that for the first time—I hadn't ever gone through it at one sitting—and picked out about four or five letters that people had written to me, and selected some salient points that they were making about the way that I cared for their loved one that they found particularly comforting. I just read them these letters, and then we discussed the various points that were being made. I let the letters speak for themselves as to how important I thought these principles were. It was very effective.

Hughes: Yes, I can imagine it would be.

Bolan: I think I'll probably do it again this year.

Hughes: Quite a different tactic than having them read a text.

Bolan: Yes, right. The first year, and maybe the second year, is when you've got the time to instill a lot of these principles in students, before they become overwhelmed with clinical responsibilities and the press of daily events and frustrations of taking care of multiple patients with different diagnoses in a hospital setting where there's all sorts of things going on and it's very chaotic. If you wait until that point to start to infuse these values or really hammer them home, you've missed the boat, because they've become cynical and angry and frustrated, and they view the patient as enemy, as another problem that's sitting in front of them that's between now and going home.

I consciously made the decision at some point in the last couple of years that I wasn't going to be able to continue to just see patients on a one-by-one-by-one basis. Even if I were able to bring more hope to them, I needed to do something to have a multiplier effect on my energies. And teaching was one of them.

Medical Director of HIV Services

Bolan: I was recruited to come to USC and direct HIV services for the Department of Family Medicine. USC has plenty of HIV presence and credibility and plenty of HIV research in the Department of Medicine. But the Department of Family Medicine and primary care really don't have a unified approach to health care that will embrace the concepts of managed care as they need to be. So since
I've had experience with managed-care organizations in the context of taking care of people with HIV disease, I was a pretty attractive candidate for them. I wasn't actively looking for a position or for another opportunity. They came to me. But I was ripe for the picking.

So right after I came, for the first six months, it was really pretty frustrating, because my decision in coming was based upon the belief that USC was going to develop a capability of doing managed-care contracting in pretty short order, getting some HMO contracts, and attracting a new patient population that they previously hadn't had. The reason that that's important is that when managed-care organizations come to employers and begin to offer their HMO products as one insurance plan, then the employer begins to drive what kind of health care the marketplace is going to have. People who are employed by these employers are going to choose the HMOs a lot of times, because it represents lower out-of-pocket health care costs to them. And the HMOs, for all of their evil marketing strategies, will promise you the sun, the moon, and the stars if you come on board, and then some of them will do a little bait-and-switch and make life difficult for you once you're on board.

The point is that the market becomes a more employer-driven marketplace, and if USC were able to get all of these various kinds of contracts with HMOs, then the patients would come. That's been shown in every major city that HMOs come into. You don't have to market USC; you don't have to apologize for it being in a bad part of L.A., all that kind of stuff.

Well, that didn't happen. The organizational thrust hasn't happened yet. They're still working on it, but to my way of looking at it, they're going to be working on it well into the next century. In many ways, it's a really dysfunctional organization, like many universities. The departments are set up like feudal systems.

Medical Director, Los Angeles Gay & Lesbian Services Center, 1996-present

Bolan: So I was beginning to get pretty frustrated that I'd really made a horrible decision to leave my practice and my friends and the climate and all the wonderful things in San Francisco and Mill Valley to come to L.A. But then this opportunity came up that was just far beyond my wildest imagination as to what I was going to be offered to do. The L.A. Gay and Lesbian Services Center, with
its large HIV Clinic, 2,000 or so, HIV-positive patients, was looking for a medical director and had recently been fortunate to bring on board a very skilled and capable health administrator, Keith Waterbrook. A skilled health administrator is something that the organization had never had before. They had community-based organization administrators that didn't know anything about health, and they didn't work out very well.

So Keith's presence and expertise made it a much more attractive opportunity. So I've been the medical director there since the beginning of May. We're turning the whole organization around in the way that it delivers health care, going from a mid-level practitioner model, where physicians assistants, nurse practitioners, and nurse clinicians are primarily seeing the patients, changing that to physicians caring for patients with nurse case managers and mental health providers integral members of the team.

Then we're also going from a total reliance upon public funding to being able to bill for people's insurance. We're working out a plan right now so that we'll be able to do contracting with HMOs and with the state for Medi-Cal contracting. This is a big deal. We're the second largest provider of HIV services in L.A. County. So in one snap of the fingers, I was able to move into an opportunity that was far beyond what I really had ever envisioned that I would be able to do. So it's a lot of work, a lot of hard work, but I've got a vision.

Hughes: You've got your multiplier effect on two fronts.

Bolan: On two fronts, yes. And that feels really good.

As I knew I would, I really miss the intense clinical contact, and there was a long hiatus where I wasn't seeing very many patients at all. Now that I'm starting to see more patients again, I'm really feeling a lot more whole and complete.

Hughes: So you're not just an administrator.

Bolan: No. I did a spinal tap this afternoon. I've got two patients in the hospital right now. I'm a real doc again, and it really feels good.
Conceptions of AIDS

The CDC Definition

Hughes: Let's go back. I am wondering where the CDC definition fitted into your practice, how much it counted, and how much it limited you, or did it?

Bolan: Well, the CDC definition was always advertised as an epidemiological tool. It was a surveillance definition. Fortunately, with all of my previous years of experience in real-world epidemiology, I understood the significance of that, and I didn't let it hinder me or hamper me clinically in any way. I didn't let it force me into a box.

Hughes: Could you expand a little bit on the difference there? How an epidemiological definition might differ from what you in clinical practice would actually apply?

Bolan: Okay. Well, the original definition was meant to include all cases of immunodeficiency due to this new disease. And in order to have a tight definition, you wanted to make sure that all the people that you put into that category had really indisputable indicator diseases that were absolutely not seen in any other conditions. So the original surveillance definition was developed at a time before we had the HIV test, before we even knew that it was definitely a virus-caused disease.

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Bolan: Then when the virus was discovered and first termed HTLV-III, the surveillance definition was changed to incorporate that knowledge. And CDC broadened the definition a little bit at that point, and I can't remember exactly what they added. There were certain conditions that, with a positive HTLV-III antibody test, could be included in the surveillance definition. I believe pulmonary tuberculosis was one of those. I'm not sure whether that was the first thing that they let in the door with a positive HTLV test. It wasn't a condition that could only occur in people with HIV disease.
AIDS as a Disease Spectrum

Bolan: At some point, though, after HIV became described and known, it began to dawn slowly on us that the consequences of this infection were a spectrum all the way from asymptomatic, through what we were then calling AIDS-related complex or AIDS-related conditions, to AIDS with severe indicator diseases. Once we began to understand that spectrum, those of us who were clinicians began to steer away from the CDC's definition, because it wasn't clinically relevant for us any more. We understood that it was a spectrum, but the CDC's definition didn't conveniently group conditions according to that concept.

The genesis of the term ARC was probably born out of an intention to broaden that case-finding net, but to make a different category, and to say, "We're going to group rather than lump, because we don't know whether we can lump yet."

Hughes: You mean separate group.

Bolan: Separate group, yes. Like two separate groups with a dashed line in between.

Hughes: Always seeing that there must be some kind of connection, but not--

Bolan: Yes, but not being bold enough to declare that it was in fact a smooth spectrum.

Now, at some point, the use of the definition of AIDS for disability purposes became more and more important. Early on, when people progressed from symptoms of any kind to rapid development of various indicator diseases, people weren't spending long periods of time with sickness so profound that they would be disabled but without having an opportunistic infection. It was a collapsed course. With the advent of prophylactic treatment and then AZT and then ddI and so forth, we were able to make earlier diagnoses, prolong people's lives, but find that there were people who developed symptom complexes that became disabling without having an indicator disease that classified them as AIDS.

Hughes: Can you give me an example?

Bolan: Wasting syndrome, for one. Chronic diarrhea and fatigue, without necessarily wasting. Repeated respiratory and bacterial infections, sinusitis. Those were three of the most common things.
Hughes: Did you say to yourself, These are patients with HIV?

The HIV Antibody Test

Bolan: At this point, yes. There's another little facet that I'm forgetting here, and it's an important one, and that is the politics of the HIV test. When the first antibody test was developed in, I believe it was May of '84?

Hughes: Commercially tests are not available until March of 1985.

Bolan: All right, so it was March of '85. Let's see. [Luc] Montagnier and [Robert] Gallo's papers were in late '83.

Hughes: Yes. Margaret Heckler's announcement of the discovery of the virus was in April of 1984.

Bolan: Gallo's paper was '83. I think--

Hughes: People were pretty convinced--

Bolan: Yes, by that time.

Hughes: --that it was a virus.

AZT

Bolan: The first commercially available antibody test was not until '85. So there was a period from March, April of 1985 until April of 1987, two years, where there was no treatment available for HIV. AZT became available in October of '86 but was only for people who had had PCP, I believe. They had to have fewer than 200 CD4 cells, and they had to have had PCP.

Hughes: Because there was so little AZT available?

Bolan: No, because that was the group in which benefit was first shown. As with many other diseases, treatments are studied in the sickest of the people who have a certain disease. I think the logic goes that, if you've got a treatment that you really don't know whether it's going to hurt or whether it's going to help, why not offer it to people who have no more hope, who you can't hurt much any more? As it turns out, that's sort of counterintuitive in a way; if
you're really looking for something to be effective, you probably would like to apply it at the earliest point in the course of a disease so it doesn't have to overcome all this other pathology and weakened host to rise to effectiveness. But there you have it.

In April of '87, the indications were broadened so that we could provide the drug to people who had an ARC diagnosis. Of course it was also a manufacturing problem as well. The first expanded access trial was with AZT, and I really don't remember how long it lasted. I think it went on for a few months—I don't remember exactly when it was approved. Sometime in '87.

Reluctance to Take the Antibody Test

Bolan: The point is that during that two-year interval, there was nothing that you could offer somebody with a positive test. We hadn't even established at that point that prophylaxis against Pneumocystis pneumonia was worthwhile. Looking through some of these materials here, I came across an article—oh, in fact, it was probably that Time article—where either Gottlieb or Dan William talked about providing prophylactic treatment, and they could only have been referring to prophylaxis against opportunistic infections. But I know that we didn't begin to do it in a widespread manner until early '87 or probably even late '87.

So people said, "Why be tested? What good is it going to do me to know? I may lose my job; I may lose my insurance; I may get thrown out of my apartment." My party line at the time—it's documented in all kinds of things that I wrote at that time—was, "I understand that. I don't have an argument against that. But if getting the antibody test and knowing the results of the antibody test would help you in your resolve to adhere to safe-sex behaviors, then do the test." That was the only argument that I could think of.

Hughes: Did some people buy that argument?

Bolan: Yes, some did. I don't know how many, but some did.

The reason that I went off on this tangent was we were talking about clinical decision-making and the CDC definition of AIDS and ARC and all that. So there weren't very many of us that were using the HIV test to help to define whether a person's clinical syndrome was part of the HIV spectrum. We had several
clinical criteria that we had established, and there's a list someplace in the BAPHR documents of proposed criteria for making an ARC diagnosis—the presence of so many clinical things. And it's pretty clear that if you use that list, everybody that you put in that group is going to have HIV disease. Thrush was part of it, and so forth.

Drug Treatment and Testing

AZT and Aerosolized Pentamidine

Bolan: I can't really exactly remember when it was that clinicians began really using the HIV test to help them sort through difficult clinical dilemmas with patients. I have a feeling it was probably somewhere around—oh, I'll say 1989, 1990. Because when AZT became available, the push was to have people tested so that we could see whether they would be appropriate for AZT therapy. So that was the first motivation to give people the test, because you could do something for them. And then when PCP prophylaxis became well established by '88, '89--

Hughes: When you say PCP prophylaxis, are you meaning aerosolized--

Bolan: --pentamidine.

Hughes: Pentamidine had been around for the duration of the epidemic, right?

Bolan: We were using it for treatment, but not routinely for prophylaxis.

Hughes: Why?

Bolan: We didn't know that it would work. The first study that showed that it would work was done in San Francisco through the Community Consortium. We all participated in that.

Hughes: Were you involved with that group?

Bolan: Yes, sure. I had, I don't know, twenty or thirty patients in it, something like that. And that was in '87.

Hughes: Why so late? If pentamidine was around, why did it take until 1987 to do the proper clinical trials?
Bolan: I think the answer to that is that we were using it before then, but we were using it as a presumptively good idea. I can't remember when we started to routinely recommend prophylaxis for PCP, and started to use Bactrim oral prophylaxis. I'm sure that we started to do that before late '87, but the study to prove that was right was still in progress. I don't remember exactly when that study was started. It must have been in '86, because my recollection is that it ran for about a year, nine months or a year or so and finished maybe in August of 1987.

The Patient as Research Laboratory

Hughes: Is there a principle here, that physicians can play around with a drug or a procedure or whatever, but until there is an accepted scientific trial of some kind, it is just sort of a random trial? It's not tried-and-true methodology.

Bolan: Absolutely. That goes on all the time in medicine. That's going on right now, every day, with HIV. That has been the principle of the epidemic: the laboratory is in the field. The laboratory is in every examining room and every provider and every patient face-to-face encounter and every decision that's made. All of medicine, even without regard to HIV, is experimentation in some degree or another.

The way that we bring order to that experimentation is through our carefully controlled clinical trials. And the reason that we know that we need those things is that observer bias, case selection, nonuniform dosing regimens, different burdens of disease—all of these things and many more affect outcome. And unless you carefully control for all of these variables, you may not get to an answer or you may come up with the wrong answer.

But it takes time to do those studies. It takes time to write the protocols, agree on all the inclusion and exclusion criteria. It takes time to do the statistical analyses of how many cases you're going to need. It takes time to get them approved through the institutional review boards. It takes time to get them funded. It takes time to recruit the patients. One of the most frustrating things about clinical research is that from "I've got an idea" to breaking of the code to find out who got what drug and what the outcomes were is usually not less than a two-year process.

And what happens in the meantime? The landscape changes. The landscape changes dramatically. We learn more about the
natural history of the disease. Newer monitoring tools become available that are more precise ways of defining disease stage, which means that many times the accepted guiding principles of a study that were laid down at the beginning become outdated at some point during the course of the study.

Clinical researchers and clinicians and patients, we all understand this dilemma. We all understand the importance of doing carefully controlled clinical research, but we realize that we're in a real-world laboratory, and both we and the patients know that there isn't unlimited time to sit around twiddling your thumbs, waiting until the clinical trial tells you exactly the right way in the right dose in the right timing to do a treatment. We all know what's behind the "no-treatment" door.

So that's what drives groups like ACT UP to angrily raise a din that can't be ignored so that there are no bottlenecks, so that there's ample funding, so that there's just a constant pressure: Do it, do it, do it, because we know this testing takes a certain amount of time. Don't screw around with nonessential inefficiencies.

But in the meantime, on that backdrop are those biweekly or monthly appointments between doctor and patient: "What are we going to do? What do we think is going on? What's available? What's been my experience? What do I hear talking to my colleagues in the network of what's working? What do we believe?"

**PCP Prophylaxis**

Bolan: We started to do PCP prophylaxis much earlier than this point the Community Consortium trials, but we didn't know what was the right dosage of aerosolized pentamidine to give. In fact, the aerosolized pentamidine story is a really good example of a good idea, but not a great idea. We thought it was the best thing since Saran Wrap, because it was a horrible drug, but we could give it topically. We could give it, just inhale it, and just prevent the PCP. The stuff didn't have to get into your toenails. Well, it turns out that it did have to get into your toenails, or at least it had to get into other tissues in your body, because there were some cases of disseminated *Pneumocystis* that weren't prophylaxed with aerosolized pentamidine.

Also, we learned that the distribution of pentamidine throughout the lungs was not even. It didn't get up into the top part of the lungs, into the apices. And so when people had
Hughes: So it all takes time.

Bolan: It all takes time.

New Science, Tests and Treatments

Bolan: As an example of one of the current dilemmas that we have, in the last year or so, we've really been immersed in this new understanding of the incredible dynamics of HIV infection, and the incredible dynamics on the other side of immunologic reconstitution and immunologic battle. We know that there's a complete turnover of viral particles in probably less than two days, and that an infected person will produce over one billion viral particles a day. In the early part of their infection, they will reconstitute killed CD4 cells at the same rate, or slightly less. It lags slightly behind, which tells you why over the course of years, the CD4 count falls behind and it can't keep up.

In the last year, we've had the good fortune to have a new test that can measure both sides of that dynamic equation, with the viral load [the viral quantitation test], and the CD4 count. We've also had the good fortune of having a whole new class of incredibly potent drugs become available to us, the protease inhibitors. And we've had the incredible good fortune of understanding the critical importance of combination therapy.

So right now, the dilemma on the table is that resistance can develop to these protease inhibitors, and it can develop very rapidly if they're not used properly. There are two of the protease inhibitors that, if used in combination, can enhance each other's effects—I mean, multiply their effects several thousandfold—but we have absolutely no idea what the proper dosage to use is. There's a possibility of significant toxic side effects if you use too big a dosage.

So right now we're in the midst of this dilemma, where you've got a patient that comes in and he's virtually at the end of the line with treatment choices, and you wonder, Should I give him this possibly dynamite combination that may do a great deal of harm, because there hasn't been any research done on using these combinations? When these data were presented in Vancouver, the
message from the clinical researchers that had been looking at this was essentially, Don't try this trick at home yet. But I can tell you that people are going to try this trick at home. I'm going to try this trick at home. When you're so far down the road, what the hell do you have to lose? And the patient should be able to make that decision. They should be able to say, "I'm not ready to go yet. I'm willing to take the chances."

Hughes: Your description suggests to me that several approaches are coming together, and only very recently. One, of course, being the study of the natural history of the disease, which was, I presume, what the epidemiological studies were getting at.

Bolan: Yes.

The Oncology Model

Hughes: The second approach was looking at the immune response. And then, what can we do about it? Namely, what drugs can we devise that will stop one or a combination of these processes? Is this the first time that those three lines of research have come together in a productive way in this disease? Is this what usually happens when you're dealing with a new disease?

Bolan: What I'm thinking about right now is the oncology model. What we have been doing all along, whether we knew it or not, was very much an oncologic approach to a formidable disease, in that when a person is diagnosed with a cancer, you have several different kinds of treatment options. You've got surgery; you've got radiation; you've got chemotherapy; you've got immunotherapy. All of them aren't appropriate for all cancers. Some of them are totally ineffectual for some cancers. But I think it's fair to say that all cancers are going to find a treatment home with some combination of these tools.

We do that in HIV disease. We've been doing that in HIV disease from the beginning. The difference, perhaps, between the oncologic approach and what has historically been the HIV approach is perhaps the orderly manner in which oncologic work proceeds. As a primary care provider who works with a lot of oncologists in consultation, it's been my observation that the field of oncology is very protocol-driven. It's very classification-driven. They seem to have learned at some point in the past that the most important thing before you get to treatment is an accurate diagnosis. Well, that's a good principle in medicine in general. We all try to proceed from that principle. But it is a mantra for
them. You've got to have the entity put into exactly the right box. So they're constantly trying to juggle the boxes around to make sure that the diagnostic categories are pristine and contain examples of exactly the same thing.

Once you've got examples of the same thing in all these different boxes, then you can begin to apply treatment protocols to the different boxes. And those treatment protocols are based upon understanding of the kind of cancer that it is, the kind of tumor cell that it is, the kind of nutritional requirements that it has and potential weak points that it may have. From that understanding, you concoct a plausible treatment regimen that is either a combination of one of those four or a couple of those four tools.

Hughes: So it's a very reductionist approach.

Bolan: Extremely, yes.

Hughes: You don't take in the whole patient, the whole context.

Bolan: Yes, that's true. I don't want to give any oncologists short shrift, because oncologists are very, very good at including the patient in the discussion.

Hughes: We had a conversation about patients describing symptoms that you couldn't necessarily categorize but you didn't dismiss.

Bolan: Yes, and that is perhaps different. I think it's probably fair to say that in oncology, most of the cancers have been discovered and defined. It may take some time in an individual patient to go from knowledge of a type of cancer to the exact definition. I can't think of any instances that I've been involved with where you haven't finally come to that analysis. And with HIV, you always have this nagging doubt that what is presenting to you may be A, B, and C that you can define, but there may be D, E, and F that you haven't got a clue about. So you do have to have an image of an explorer loping through the bush, with instruments falling out of his pockets. [laughter]

Hughes: That's a good image. The process with HIV is open-ended, right?

Bolan: Yes.

Hughes: But the oncologists are trying to get things signed, sealed and delivered, would you say?

Bolan: I think that's right.

Hughes: Put into boxes and categorized.
Bolan: Yes. We're trying to do that with HIV, but we know that there's still too much stuff that we've got in our hands after we've got all the known boxes filled. We desperately want to do that, fill the boxes, because we know that in that way lies clarity of treatment options.

Hughes: Is that a realistic expectation of a disease that manifests itself in a myriad of ways?

Bolan: That we will eventually be able to understand all that stuff?

Hughes: Yes.

Bolan: Yes, probably.

The Challenges of HIV Disease

HIV as a Modifier of Pathology

Bolan: A long time ago, I understood one of the most fundamental principles about HIV, and that is that HIV modifies everything. It's the great modifier.

Hughes: "Everything" being other diseases?

Bolan: Other diseases, other conditions. So if you had it in your gene pool to develop psoriasis at age forty-two, chances are if you have HIV, you would develop it at age thirty and it would be a rip-roaring son-of-a-bitching case. And that principle holds true from psychiatric disease all the way down to the toenails. So when you approach HIV disease clinically with that guiding principle, you rarely get fooled. You also don't necessarily try to lump everything into, Oh, that's just HIV disease, because you know that people can have other illnesses coinciding with it. People can have heart disease; they can have heart attacks; they can have other things. But as long as you maintain the principle of HIV as a modifier, you're not going to lump things that don't belong, and you're going to be on the lookout for peculiar manifestations of common illnesses. That's the punch line. In essence, that's the beginning and end of how to be an HIV doc. Very simple.

Hughes: Does that make it challenging and interesting, or does that make it frustrating, or something else?
Bolan: Well, that's a good question, because many physicians don't really like difficult, complicated, frustrating clinical challenges. They like easily definable, embraceable, approachable, treatable, let's-get-out-the-door types of entities. So not everybody can do, not everybody wants to do HIV disease for that reason.

Hughes: What about Bob Bolan?

Bolan: I find that it is continually stimulating and intellectually interesting and always challenges my skills as a physician, and that's a good thing. That's a very good thing.

Clinical Uncertainties

Hughes: Does that intellectual stimulation help to keep you going?

Bolan: Yes, it does. It always keeps me off balance, though. I've met a few cocky HIV docs, but not very goddamn many. By and large, we're a pretty humble lot. We know a handful of things, but there's a whole lot of other stuff that, when you look at a patient, you say, "Well, I think I know what's going on, but I may not know for sure." And the way that I've resolved that and made it be an interesting, stimulating, challenging thing rather than a frustrating thing is that I'm honest with myself and with my patients about the uncertainty. One of the first things that I tell people is the evidence that this diagnosis is the right answer. I tell them that there's uncertainty in it, and until we get this test or that test, or see the outcome of this treatment, we won't know for sure. To try and feign assurance when you don't have it is really insanity. Some docs do, but I can't do that.

The relationships that I always try and develop with my patients is one in which I explain to them everything that we're doing in ways that they can understand--not talking down to people or being patronizing. I pride myself in my ability to explain things to people in ways that they can really understand how I understand it. I just don't use the same language that I use with my colleagues, that's all. But the way in which I understand it in my head is the way that I try to describe it to people. I have a very kind of visual and analogical kind of a mind, I think. I understand things by analogies a lot.
Communicating with Patients

Hughes: And you can get through to people?

Bolan: And I can get through to people. I can explain the essence of this stuff to people. That really helps, because the worst thing in HIV disease is to build up expectations that you can't meet. "You will get better in three days." That's crazy. Or, "We'll be able to cure this problem." You just have to be honest with people so that when the peaks and the valleys come along, as they will, they don't despair and stop complying altogether, or worse, run off and try to find somebody else who can solve their problem.

Another benefit of that kind of close communication is that you really have an honest dialogue, with what seem to be achievable goals, and my honesty with them includes whether I think this is an achievable goal. And if I don't, I tell people, "We're not going to be able to stop this. We may be able to ameliorate it; we may be able to temporarily turn it off, but we aren't going to be able to fix this." And if I can get people to really understand, adapt to that reality, it reduces the level of tension in the relationship and the fear on the part of the patient, and the demand for yet another test, yet another drug, yet another consult, to find "the answer."

And what am I talking about? I'm talking about appropriate utilization of health care resources. So I think one of the real secrets in appropriate management of these precious health-care dollars that we have is rooted very firmly and solidly in the doctor-patient relationship, and in the collaborative, ongoing, continuous relationship, so that you can develop a partnership that doesn't lead to chaotic demands and decision-making. It's very important.

Hughes: It sounds very appropriate, not only from an economic but from a human standpoint.

Bolan: Of course, and that's really where it started. But I just discovered the economic part of it much later, and I thought, Oh, this is cool.

Hughes: The field came around to your thinking.

Bolan: Exactly. [laughter] But yes, it just seems that the worst fear that a person with a bad problem can have, as far as I can imagine, is that their physician, the person that they've invested all their energy and hope in, doesn't understand them. Doesn't understand what they're trying to say, or just doesn't get it,
doesn't understand them. I mean, that's--. I don't think that I am arrogant about my confidence in my knowledge and understanding of my patients. And the reason I say that is because I'm always testing it out. Do you understand what I'm saying?

Hughes: I do.

Bolan: I say that to my patients too: "Do you understand what I'm saying? Are we on the same wavelength here? Is there anything else that I need to know or that I don't quite get?" And when you have that kind of a relationship with people, then there's plenty of room for saying, "I don't know." You make it safe for saying, "I don't know." The whole purpose is to be able to say, "I don't know yet, but it's obviously important, and we're going to do our best to find out."

But as time goes on, there are some things where you just have to say, "You know what? That particular problem, while annoying, isn't going anywhere. We can't fix it; we can't make it go away, so why don't we let go of a little bit of fear for what the possible significance of it might be, because it doesn't seem to be very significant." So it's not quite a "get over it" message, it's a gentle, "I think this is one of the things that you're going to have to put up with, and I leave it to you to do that."

Bay Area Physicians for Human Rights

Viewing AIDS as a Passing Phenomenon

Hughes: Well, after a very interesting diversion, shall we return to BAPHR?

Bolan: Yes, please.

Hughes: You were chairman of BAPHR's KS task force [June 1981-June 1983], which was the first tangible sign of the organization responding to what we know now as HIV disease.

Bolan: Yes.

Hughes: What were you trying to do in those very earliest days of the epidemic?
Bolan: I think what I was trying to do in the very early part of it was to understand the scope of the problem, and even hope that by careful, diligent looking, that we would figure this out quickly and get it over and done with and move on to the next thing.

Hughes: Did you think it was a real possibility that you and your colleagues and science and medicine in general would solve this problem?

Bolan: Yes, I did.

Hughes: Was that a common expectation?

Bolan: I don't know, because I didn't share it very much with anybody. In a way, the epidemic was a slowly unfolding horror. It unfolded over a period of a couple of years before we really grasped its impact.

Hughes: I would think from a personal, psychological standpoint, you'd almost have to think that.

Bolan: Yes.

Hughes: If you really thought, This is an overwhelming problem that will--

Bolan: Be with us for the rest of our professional lives--

Hughes: --how would you have kept on? Also, there were precedents which might have misled you. You had the recent example of Legionnaire's disease, for example, for which the etiology was solved rather quickly.

Bolan: Yes, exactly. I don't remember when that hope faded away in regard to HIV. It was probably some time in '83. I think it was after the blood transfusion cases.

Hughes: As a result of the cases mounting?

Bolan: The cases mounting, and the blood transfusion cases in December of '82 signalling clearly that this was an infectious disease, and it wasn't any of the infectious diseases that we currently knew. So I think the hope for a quick solution was pretty much dashed at that point.
Bolan's Activities at BAPHR

Bolan: My initial effort was to use that Task Force in BAPHR as sort of an information clearinghouse to educate ourselves and, if there was education to be done in the community, to help do that. Those were the intentions of it, I think.

Hughes: And why you?

Bolan: Well, I think again, it's because I was the most activist member of BAPHR at that time, with regard to medical issues. I think that's fair to say. There was one other person, whose name I don't remember right now, who moved away very shortly after we started this.

Hughes: What are you thinking of when you say "activist"?

Bolan: I guess what I mean is meeting with the public health department—Maybe "involved" is a more appropriate term, but activist from the standpoint of being vocal, that this is important; this is a bad problem; we've got to pay attention to it; we've got to do something about it. So in the sense that there weren't people standing around on the street corner doing that sort of thing, that's what I mean by activist.

BAPHR Goals and Institutional Relationships

Hughes: You said off tape that you were disappointed--I don't know if "disappointed" is your term; it's my term, I guess--in the fact that you found that BAPHR in general was not activist--

Bolan: Enough for my taste. Yes. And so I was given plenty of latitude by the other members of the organization to pursue that mission. They acknowledged that this outbreak was very important and they were happy that I was stepping up to the plate. Why me? Because I stepped up to the plate is all.

Hughes: Could BAPHR's hesitation, or whatever term you want to use, have been somewhat because it was in a sense an organization with two heads? It was a medical group, which has a certain connotation to it. It was also a gay group. From reading through the BAPHRONs, I learned it was in a sense a safe haven for gay physicians at a time when there were a lot of unsafe places.

Bolan: Yes, that's absolutely true. And those were the dual purposes.
Hughes: And sometimes conflicting?

Bolan: Yes, those were the dual purposes that sometimes conflicted, and that's when I had problems with the slowness of the organization. I can't really think of any specific events right now, but it was just an overall tone and tenor of caution. "Let's talk about this, and let's discuss it to death," rather than, "Let's act." Those were the things that I kind of lost patience with. But it was a medical organization and a forum and a gay physicians' forum, and it had respect in the community, because the organization was out. We marched in the gay parades every year. So I think that in many ways, people didn't expect much from BAPHR, because they recognized that it was a safe haven organization first, and I was just pushing it to do something more.

Hughes: What about its relationship with the KS Foundation, which was after all the KS Research and Education Foundation. Education was a big thing.

Bolan: That's right, I forgot all about that.

Hughes: Wasn't there an overlap?

Bolan: There was definitely an overlap, and I think the reason that there was an overlap was because Marcus in particular perceived BAPHR as being slow and ineffectual.

Hughes: So he created an organization that he thought was going to move faster?

Bolan: Absolutely. I think that if you asked him that, he would say yes, he agrees.

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BAPHR's AIDS Task Force

Hughes: In 1983, March to be precise, BAPHR's AIDS task force issued a report which consisted of an extensive list of objectives and activities. I wonder if you'd comment.

Bolan: These are from my files?

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1 BAPHR AIDS Task Force, report #2, March 6, 1983 (Bolan papers, UCSF Library, folder: BAPHR Scientific Affairs Home File, AIDS/Minutes, Correspondence).
Hughes: Yes.

Bolan: I don't remember this. This list is very extensive. I'd have to look at each one to see how many we really did act on.

But looking at this other document here about the AIDS survey, this AIDS survey that was proposed was really more of a cataloguing of clinical symptoms and some laboratory findings, and I don't believe it was part of the behavioral analysis.

Hughes: No, it was described as a study of the natural history of AIDS.

Bolan: Even though the document itself does not have a date on it, at the end, it says, "The duration of the study will be limited to three years, ending December 31, 1985," so this document was late '82.

Hughes: At some point, that document says that the research project is to begin in January of 1983. Is it an attempt to gather data from clinical studies?

Bolan: Just from clinical practices, because the participants in that study were docs like me.

Hughes: Was the study conducted in a formal way?

Bolan: It was started, but I don't think that it got very far, partly because it's very difficult to gather survey information like this in a practice setting when the person asking the questions and filling out the forms and submitting the data is the physician who's seeing the patient and trying to take care of the health problems.

Hughes: Because there's too much to do?

Bolan: There's too much to do. It just doesn't get done. That's certainly been my experience in my practice and in many other practices. It's the continuing lament of private physicians who are being asked to participate in studies.

Bolan Leaves BAPHR

Hughes: What happened?

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Bolan:  I left BAPHR. I joined the San Francisco AIDS Foundation. That's what happened.  [laughter]

Hughes:  That's not coincidental.

Bolan:  That's right.

Hughes:  You left for these very reasons?

Bolan:  Exactly, although, the simplicity and clarity of it, as I just stated, was not evident to me at the time. But I think it is as simple as that.

Hughes:  How did you explain it to yourself at the time?

Bolan:  Well, there was this one incredible year, 1983, when I first became the president and chairman of the board of the AIDS Foundation [June 1983-January 1986], when I was also the president-elect for BAPHR [July 1983-June 1984]. It was incredible because I had never been so manic in my life. Now, looking back on it at almost age fifty, I say, Could I ever have done that? Could I ever have been the president-elect of BAPHR, the president of the AIDS Foundation, had a medical practice, had a lover? How the hell did I do that? I don't have any idea how I did that. But at some point, it became obvious to me that I wasn't doing a very good job at it, and I don't remember--oh, I think I do remember what the final straw was. It coincided with my final disillusionment with being a media queen.

One of the news stations was reporting on a late-breaking AIDS item, and I don't remember what the hell the late-breaking AIDS item was. It was probably one of those situations where the New England Journal of Medicine or the MMWR was coming out with a report tomorrow, and of course, we didn't have advance notice of what that report was, because being on the West Coast, things got here later. The MMWR had their news conferences on a Thursday, and the MMWRs were mailed out on Friday, so we didn't get them until Wednesday. So the news people were constantly coming at us [BAPHR] with, "What do you think about this?" "I don't know what to think about it; I don't know anything about it."

Hughes:  Because you were their sources in the community.

Bolan:  Yes, of course.

Hughes:  They went to you rather than to, say, Paul Volberding or Marcus Conant.

Bolan:  They were coming to all of us, I think.
So I got this call from one of the news stations, which wanted to interview me, and they wanted to come to my house to get the footage before the ten o'clock news. They wanted to be there at like quarter to ten. I said, "No, absolutely not."

Hughes: "I've got a life."

Bolan: "I have a life." And I hung up the phone and I said, "Right. You have a life. You're doing too many things. Stop this madness." So that's when I resigned from the president-elect position. I don't remember exactly when that was.

Hughes: I've seen the letters in your papers. How was your resignation received?

Bolan: Oh, it was received well. How could all of my colleagues be looking at this madness and think that it could continue? So they weren't surprised.

Hughes: But you continued as president of the AIDS Foundation?

Bolan: Oh, sure.

Guidelines for Sexual Activity in the AIDS Epidemic

[Interview 3: August 15, 1996] ##

Formulating Guidelines in 1983

Hughes: Dr. Bolan, we've been trying off tape to date the first BAPHR risk guidelines, and because of an editorial that you wrote in The BAPHRON in January 1983 in which you indicate that the risk guidelines are yet to be formulated, we're coming to the conclusion that somewhere around April or so of 1983, BAPHR came up with a brochure, which unfortunately is undated. Were they the first guidelines anywhere directed at HIV?

Bolan: Gee, I don't know whether they were. It's possible that New York Gay Men's Health Crisis might have come out with something. We were often very close, neck and neck, on developing things. But I believe that these were the first comprehensive guidelines that attempted to address the specific risks as we understood them of acquiring AIDS. Because I was quite involved with these, I know that they had their roots in the previous guidelines of the
Hughes: Did hepatitis B figure in your thinking as well?

Bolan: Absolutely, because as I think I state here in this editorial in January of '83, we hadn't yet discovered the virus. The announcement of the transfusion-related cases of HIV clearly signalled the fact that this was a transmissible, infectious agent, and that all speculation about immune overload syndrome was not correct. Furthermore, the epidemiology of the new cases of AIDS seemed to follow the same epidemiology as for hepatitis B. In other words, that of a primarily blood-borne pathogen, but one that could be transmitted through sexual activity. So the guidelines that we came up with for behavioral risk reduction were modeled after that concept, and were therefore pronouncements that would be applicable for hepatitis B as well.

Hughes: Those guidelines turned out to be pretty good.

Bolan: Absolutely true. Still is true. Recognizing that the epidemiology of HIV was parallel with hepatitis B was what put us on the right track, and we've stayed on that track ever since.

I remember all of the meetings and discussions that went into the formulation of this guidelines document, and they did occur in the setting of BAPHR. I definitely remember that Steven Follansbee² was part of this discussion, because of two items here: "How are we susceptible to infections?" and "What are natural barriers, and are there other barriers besides the natural ones?" Those were concepts that Steve brought to the discussion. His contribution, I can remember was the idea that our immune mechanisms were not comprised simply of antibody production and the taking of antibiotics to eradicate infections, but that there were also natural barriers like skin, mucous membranes, acid in the stomach, things like that.

Hughes: He was speaking as an infectious disease specialist.

Bolan: As an infectious disease specialist. I thought, [snaps fingers] Damn, that's clever. Wish I'd thought of that. [laughter]


² See the oral history with Stephen Follansbee, M.D., in this series.
Hughes: Was there also talk of the cellular mechanisms of immunity--interferons and interleukins and all of that?

Bolan: I don't believe so.

What we tried to do in this document was very definitely an extrapolation of the NCGSTDS guidelines, and that was to give people a context, to explain to people why we were recommending certain specific behavioral changes. That's why this is kind of a primer in what is AIDS and how is it transmitted. So I think as a health education and behavioral change document, it is a template or a model--I'm not sure how original it was with us--that continues into the present time.

Classifying Risk

Hughes: Well, another thing that you try to do is to classify sexual practices into three categories, namely, safe, possibly safe, and unsafe.

Bolan: Right.

Hughes: Are those categories that had been used before?

Bolan: Yes. A concept that we used in the NCGSTDS guidelines was to categorize risk into degrees, not only in terms of behavior. I remember with those guidelines we also mentioned places where you had sexual activity: bathhouses, and places that would have multiplier effects because in those settings, you would be more likely to have contact with other people who had a lot of sex, and it would be much more likely for an individual to be infected with something that could be transmitted.

So why did we do that? [pause] I'm trying to remember exactly where the idea [came from] that sexual behavior was obviously a highly valued behavior, and that different people were strongly invested in certain behaviors, less invested in others, and that varied from person to person. I don't remember where that concept started. I think it started back with the NCGSTDS guidelines, that we realized that a message that said, "Don't have sex," was absolutely absurd and not going to be heard or taken seriously whatsoever, nor did we want to give that message. We realized that there were safe ways to have sex where you wouldn't transmit infectious agents, and we wanted to give people alternatives to high-risk or risky sexual behavior.
I think that one of the mistakes that we made early on was in the naming of a category "safe," rather than its current name, which is "safer." As I have been saying for many years now, the only "safe" sex is across a crowded room, [laughter] waving at your partner about whom you're having lewd, lascivious thoughts.

Hughes: So it was a new concept, that in a practical sense, there's no "safe."

Bolan: Right. Whenever there's contact, there's risk.

Hughes: That isn't something that you had drawn from your previous experience?

Bolan: Yes, and I think that that was both a manifestation of the fact that we didn't have the specific epidemiologic knowledge, behavioral epidemiologic knowledge, and number two, we were hoping--this is where the educator's denial comes in--that our messages wouldn't have to be so prescriptive as to essentially render willing participants asexual. We were unwilling to believe that. [tape interruption]

Hughes: Bob, we're trying to figure out when you were first thinking about putting sexual practices into three risk categories, and when you actually put them out to the public in that form. You have some thoughts.

Bolan: Yes. Looking through these documents that I've got in front of me, I find one that is dated February 19 of 1983 by AAPHR [American Association of Physicians for Human Rights] that is really the pared-down version of BAPHR's more encyclopedic version of risk reduction. In neither this document by AAPHR in February of '83 or the one by BAPHR which we think came out in April do we talk about those categories: safe, possibly safe, and risky. Here's another from Southern California Physicians for Human Rights which is dated--well, actually, I don't know when it's dated. It's accompanied by a news release dated in February.

Hughes: Of '83.

Bolan: Right. And here is a letter from Mark Johnson from the Mullican Medical Center in Artesia [reads aloud]: "I've enclosed our recommendations for the acquired immunodeficiency syndrome." So in terms of when did we start calling it AIDS, well, by early '83,

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1 The unpublished documents referred to here and throughout the oral history may be found in Bolan's papers archived in UCSF Library.
we were definitely calling it AIDS. Their document doesn't talk about those categories of risk.

Hughes: Well, you may have been hesitant to publish those categories, but what I'm suspecting is you were probably thinking that you wanted to, because what you definitely did not want to say is that sexual activity is bad and should be stopped.

Bolan: Exactly.

Hughes: You were trying to find out and then publicize what kinds of sexual activity were probably okay.

A Defining Principle: Body Fluid Exchange

Bolan: Yes, exactly. As I look through the handwritten notes here, I remember a little bit more of the process. I don't remember any specific discussions about not including those categories, but what I do remember is that we hit upon exchange of body fluids as the guiding principle, the defining principle, that would organize sexual behavior risks.

As a curious sidelight, I'd like to tell you where that very important term, very important concept came up. Paul Boneberg was a political community activist in San Francisco, and still is, as far as I know. I don't remember what organization he was affiliated with at the time. But when we were all struggling with how, in the absence of the specific behavioral epidemiology, to formulate messages that people would hear and reduce risky behavior, he was the one who added the "exchange of body fluids" insight. There were a number of us at a community meeting at Lia Belli's mansion in Pacific Heights, in a big ballroom on the second or third floor. And we were talking back and forth about the difficulty of making clear statements and clear messages. We were also talking about what we knew about how HIV seemed to be transmitted, and we were talking about the analogy to hepatitis B.

Paul doesn't have any medical background at all, as far as I know. He certainly didn't at that point. He stood up and he said, "Sounds to me like what you're talking about is not exchanging bodily fluids." And it was like, all of a sudden, the illumination in the whole room went up about several hundred candlepower as all these lights went on over people's heads and we realized, That's it. That is the concept that we've been looking for. And that became the cornerstone for crafting all of the educational messages from that point on. So the idea of risk
categories kind of fell by the wayside, I believe. That's my recollection of why we did that.

Hughes: So it was, "Don't exchange body fluids."

Bolan: Right.

Hughes: Now, did people really get that? I think it was Jim Campbell who told me that he remembered arguing against using that terminology. I may be putting words into his mouth, but I think he said that people wouldn't understand or might use it as a tool for their denial, namely, bodily fluids mean semen but certainly not saliva.

Bolan: Well, I know that not everybody bought into that concept. The main people who didn't buy into the concept were those who didn't want to consider saliva as a body fluid and wanted oral-genital sex and kissing to continue to be absolutely 100 percent okay. I don't remember Jim taking that slightly different tack that people wouldn't understand. But about thirteen seconds after hitting upon the idea that body fluids was an important concept, we realized that we had to carefully define what we meant by body fluids, and what we meant by exchange.

Hughes: And did you?

Bolan: Yes. And that's why in the development of these guidelines, the concept of natural barriers became very important. The skin is a very important natural barrier, so if you get someone else's body fluid on your intact skin, that barrier will protect your inner core from any infectious agent that's in that body fluid.

Hughes: Unless you have cuts.

Bolan: Unless you have cuts, yes. So the direction that we went in, was more, We have a conceptual model here that is better than high-risk, low-risk, medium risk. Although later on we reintroduced those terms to supplement and help to order the degree of risk. Safe, safer, low-risk, and possibly risky, definitely risky, high-risk—all those terms were used at one point or another in transition or in parallel. If you look through those lists, the concept of bodily fluid exchange is exactly parallel to that.

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1 See the oral history with James Campbell in this series.
Backlash

Hughes: Do you remember how these first BAPHR guidelines were received?

Bolan: Oh, probably with the same enthusiasm that any of these guidelines are received. That is to say, some people took them to heart and tried very diligently to follow them. Other people looked at them and found that their favorite sexual activities were the ones that were the highest risk. They had absolutely no interest in putting any credence in guidelines that were going to be giving them messages that were so counter to their important values. Anger, accusations of homophobia for those who were promulgating these guidelines.

Hughes: Even though it was BAPHR which was behind the guidelines?

Bolan: Oh, sure. I was definitely the target of several comments, statements, letters, phone calls, even though it was clear to them that we were trying to tell them something. Anger and denial was all that it was.

Hughes: They couldn't logically call you a homophobe.

Bolan: Well, some thought they could, because they thought that I was trying to use the excuse of this, in 1983, largely invisible epidemic, invisible to the majority of healthy, sexually active gay men-- Remember, in mid- to maybe even late 1983, there were still not a significant number of men who knew people who were sick. In fact, I think that Larry Bye's questionnaire asks the question, "Do you know anybody with AIDS?" I don't remember exactly what the figure was, but I know that it wasn't much greater than 25 percent in mid-1984. So in 1983, it was even lower.

So you had a very high disbelief quotient that was playing here, and people who look at the law and government as cracking down on a group of people, using an excuse--in this case, public health, but in many other instances like this, other things. People said such things as: "It is very easy to see that this is an inappropriate crackdown on us. You haven't the evidence to do this. How dare you? And how dare you, being a gay man, do this?"

Hughes: In a way, with that mindset, it made it worse that you were a gay man.

Bolan: Of course. I remember very clearly a community meeting at the Valencia Rose about closing the bathhouses--this is outlined also in my interview with Gerald Oppenheimer. I was there with Merv
Silverman and Ric Andrews and I can't remember who else. Merv wanted to present the reasons for closing the bathhouses at this community forum, town hall meeting. And when Ric and I stood up there to deliver ourselves of our support of this notion, we were almost pilloried on the spot. I've never before nor since been in such a charged atmosphere with so many hundreds of eyes directed personally upon me in a really hateful manner. It was frightening; it was awful. It was the worst experience I've ever had in my life.

I ran out of that meeting at the earliest opportunity I could, and drove home almost literally quaking in my boots, thinking, What am I doing? What have I done here? What's the story? I'm a private practice physician. I'm a small businessman. I'm delivering messages to my customers that people don't want to hear. What the hell kind of business sense does that make? That was my first personal/selfish reaction. Believe me, when all of us were taking strong positions, we all had doubts to greater or lesser degrees as to the justification for these positions. There was always room for debate on the other side of the issue. So when the resentment ran high, those of us particularly who were volunteering our services got a little bit more nervous. At least Merv was getting paid for doing this. [laughs] It was part of the job description.

Hughes: Did you pull back as a result of that experience?

Bolan: I don't think so, no.

Hughes: Another thing you could have thought was, Here I am volunteering my time and trying to protect the safety of my community, and this is what I get.

Bolan: Oh, I definitely had that feeling too, and that made me really angry and pissed off. And on more than one occasion, I would lash out. I don't remember specific times that I did this, but I remember lashing out and saying, "Look, god damn it, I'm giving of my time and my life's blood for this issue. Don't attack me personally. Attack me on the ideas, but don't you dare attack me personally."

Hughes: Did people hear that?

Bolan: I don't know. [laughs] When I'm that angry, I don't listen very much. I don't hear responses very well.

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1 See the oral histories with Mervyn Silverman in the AIDS physicians series and with Ric Andrews in this series.
Hughes: Well, there was another instance of hostility. Did you attend the fifth national Lesbian/Gay Health Conference in Denver in June of 1983? There was an AIDS forum entitled, "Creating Positive Changes in Sexual Mores."

Bolan: Okay, that Denver conference is the one at which I co-chaired a session with Jim Kajeski.

Hughes: And there was an angry response.

Bolan: Oh, you bet there was.

Hughes: Had the guidelines had come out?

Bolan: The guidelines were either in their final draft, or they had just come out. The timing was, Paul Boneberg said, "I think you're talking about body fluids," and we said, "Aha." Jim Kajeski and I knew that we were going to Denver in June to chair this workshop, and we hammered and put together these guidelines.

Hughes: Who's Kajeski?

Bolan: Oh, I'm sorry, it wasn't Jim Kajeski. It was Steve Morin.-- ##

Bolan: --who was a psychologist.

Hughes: From BAPHR?

Bolan: No, he wasn't from BAPHR. He was making the transition from private practice as a psychologist treating gay men to political advocacy. He subsequently became Nancy Pelosi's chief aide and has been for years and years and years.

Anyway, so Steve was very involved with these behavioral messages early on because of his psychology background. He was at that meeting, I believe, at Lia Belli's house. I don't remember how he and I came to be asked to chair this workshop.

Hughes: There was also somebody else, whose name I don't remember.

Bolan: That's right, there were three--oh, Tom Smith, I think. Who was a psychiatrist.
Anyway, we were excited about going to this meeting with what we thought was a pretty polished conceptual framework for behavioral guidelines. And when we presented them, there was almost an instantaneous firestorm in the room. I remember very clearly Nick Ifft [spells], a physician from Philadelphia, who was so agitated about this that he felt compelled to jump up and run out of the room and go tell Roger Enlow, who was a very strong-willed, opinionated immunologist from New York who served very intensely early on and then burned himself out in the New York City Health Department. Nick ran to tell Roger that we were preaching heresy and unsupportable guidelines and recommendations.

Hughes: Because the effect would be to curb sexual activity?

Bolan: To an extent that he thought was unacceptable or unsupportable by the data. So a few minutes later, Nick came back with Roger Enlow in tow, and there proceeded a very, very uncomfortable, vitriolic, raised-voices exchange of views, and to this day, to this day, I bear great animus towards Dr. Ifft. I thought it was a weasely, cowardly thing to do--"go tell Daddy."

The end result is that it escalated this instantaneously beyond rational dialogue into diatribe, and it diluted any possible effect that we could have had by merely having a calm discussion about it. I was so incensed and infuriated at all of this angst and anger that I said to I don't know how many people, "I'm giving of my life's blood to be here, god damn it. Show a little bit more respect." And I stormed out, and I went home early.

Hughes: So it really was a break.

Bolan: Yes. I just said, "Fuck you people. I'm going home. I don't have to take this shit."

Hughes: I have a quotation from a Baphron piece about the Denver conference, entitled "A Not So Gay Event": "A crowd of angry AIDS patients, dissenting gay doctors, sociologists, and lay persons faced the panel intent upon tearing apart 'The San Francisco Secretions Thing.'"1

Bolan: Yes, that's it! [laughs heartily] Let me see it. [reading] Yes, the forum was co-chaired by Tom Smith, Steve Morin, and me. [reads aloud] "It was a reaction to the adverse result of the BAPHR position that secretions and excretions are the most likely vehicles for AIDS virus transmission. A large number of

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1 The Baphron, July 1983, 213.
participants felt the position being circulated to a large unsophisticated audience has led, and is leading, to untold grief in the Gay Community: the use of glove and masks by police, the refusal of health care personnel to visit gay patients, the firing of gay food handlers, et cetera."

I don't think I wrote this. I would have been far too angry at this point to be able to write anything like this.

Hughes: Was there any resolution?

Bolan: Well, what guidelines eventually became the most prevalent? The ones that continued in the principle of bodily fluid exchange. And maybe that helped to stimulate a modification to put them in the context of these low-risk, moderate-risk, high-risk, or safe, safer, whatever categories.

Different Audiences

Hughes: Well, another problem that it seems to me you had in creating guidelines was your audience, which fell into three categories, namely, those with AIDS, as it was called then; those that we now know were HIV-positive--

Bolan: The at-risk.

Hughes: The at-risk, that's good. And then those who thought of themselves as being healthy. The guidelines had to appeal to all three of those groups, right?

Bolan: Yes, they did. They had to exhort those who had not yet been infected to do everything they could to keep themselves from becoming infected, to exhort those that were infected from not spreading their infection, and to exhort those that were infected to not engage in behaviors that would make them sicker by getting other things. We had that concept down. We didn't have the idea of multiple HIV exposure perhaps being a bad thing, and multiple strains of the virus--no. The message that we were trying to give to those people who were already infected was to reduce the risk of further STDs, because we hadn't given up totally on this immune overload concept. We knew that there was something important about the continued onslaught of new infections. That wasn't a good thing, couldn't possibly be a good thing. [tape interruption]
The AIDS Foundation's Proposal for an Education Campaign

Leon McKusick

Hughes: Dr. Bolan, I think that's a good background for discussing what happened when you began to work on similar problems with the AIDS Foundation. Am I right in thinking that some of them were occurring simultaneously?

Bolan: Absolutely, yes.

Hughes: On June 18, 1984, the Foundation presented to the San Francisco health department an AIDS education proposal. I got that from the letter that Conant wrote a few months later to Mervyn Silverman. I don't actually have that document. Do you want to talk about the buildup to the actual proposal?

Bolan: Well, having had a chance to review some of these important Foundation documents here, I have a much clearer memory than if I had to construct it just out of memory. Leon McKusick's bathhouse and bar survey that he did in November of '83 and then a second time in May of '84 formed the basis for a lot of our plans to do an educational campaign.

Hughes: Did he initiate the surveys through the AIDS Foundation?

Bolan: No. See, there were a lot of simultaneous efforts that were going on between the health department, the AIDS Foundation, and UCSF. Those are the primary organizations. And Leon was working on his Ph.D. at UCSF.

Hughes: I see. He was a psychologist?

Bolan: Correct.

Hughes: A Ph.D.

Bolan: Well, he subsequently got his Ph.D. He had his master's level at this point. So he had a university affiliation and was primarily doing this study. I don't know where his funding came from. So there were these three organizations, or four, if you want to add BAPHR--BAPHR, the AIDS Foundation, the health department, and the university, the four thrusts.

But Leon for the first time brought to the table some specific behavioral epidemiology--the prevalence of certain behaviors, the prevalence of certain attitudes and values.
Hughes: From his surveys, not from previous experience?

Bolan: Exactly.

**Larry Bye's Telephone Survey**

Bolan: And at the same time that he was doing those surveys, the AIDS Foundation had decided that it was going to put together and launch a major education and risk-reduction campaign based upon whatever kind of analysis that we could pull together. At the same time, Larry Bye, whose advertising firm, Research and Decisions Corporation, had decided that he wanted to do an expanded database of the entire gay population, or a sample of the entire gay population, and not sample it in as focused a manner as Leon did in the bars and in the bathhouses.

Hughes: Bye wanted to get a broader perspective?

Bolan: To get a broader perspective. I don't remember whether Larry's stimulus for doing this was based upon Leon's work or not, but I doubt that it was solely based on that, because we all knew that we needed more data; we all knew that we needed effective messages and didn't know exactly how to formulate those, and we were all trying different approaches simultaneously to answer those questions.

**The PRECEDE Model for Behavioral Change**

Bolan: So at the same time that Larry was putting together his proposal to do this telephone survey, at the AIDS Foundation I was trying to take a more academic approach. People whose opinions that I respected in the behavioral specialties stressed that we knew little about prevalence of certain behaviors, prevalence of attitudes and health beliefs and so forth. We just didn't have that stuff. We could guess at it, but we didn't have it, and to do a prospective survey was going to take some time.

I reviewed the health behavior literature and found that there were no models in the health behavior literature that were directly applicable to sexual risk reductions—that were worth a damn, anyway. So I looked about for an approach that we could try and take to discover—sort of in a reductionist manner, if you
will--what likely principles we could define and build an educational campaign on.

That was the genesis of my pulling together a consultant group, and the whole methodology is really very well summarized in this August '84 letter to Jim Mason at the CDC.\(^1\) Our group was already in process by the time I wrote this, but this letter summarizes what I did. We used a published conceptual model for trying to discover what important health beliefs were in the target population, what kinds of predisposing and reinforcing and enabling facts all went to determining whether a person was likely to follow a particular health behavior or not follow a particular health behavior. This methodology was a very precise tool for sifting through a whole lot of material and distilling it into these principles, these diagnostic--they call them behavioral diagnoses. That's the terminology used by this model.

Hughes: This is the PRECEDE model.

Bolan: This is the PRECEDE model, as described by Larry Green, et al.

Hughes: Had the model ever been used?

Bolan: Not in this manner.

See, I used the model in a slightly modified way. The way that the model was originally conceived is that it is applied within a sampling of people for whom you eventually intend to fashion a behavioral program or message or whatever. It's kind of a focus-group type of approach, but rather than ask people unstructured sorts of questions, you get them to participate in a rather structured analysis of varying stages of, "What do you believe about your health and what's important in maintaining it? What are your health beliefs? What are your values in terms of behaviors that we might consider to be risky against this particular health?" You apply this discovery process on the at-risk group.

Well, rather than doing that, I drew on a wide range of consultants in sexology, epidemiology, health education, psychology, advertising, market research, and we applied the model with us as the discussants. I decided to take that route because it was easier, more manageable, and quicker to execute. I felt that it was okay to do it that way, because so many of the participants were also members of that risk group, and were very

\(^1\) Bolan to James O. Mason, M.D., Dr. P.H., August 1, 1984 (Bolan papers, UCSF Library).
conversant with the behaviors and values that we were talking about.

We met, I don't know, three or four, maybe five times altogether, and went through a pretty complete and detailed execution of this model, and came up with a whole bunch of behavioral objectives. My memory is a little bit hazy, because this is many years ago, but we came up with a whole list of specific behaviors and factors that we organized in a matrix: Those that were extremely important in terms of putting a person at risk for acquiring an infection like HIV, but were also very highly valued behaviors, or they were behaviors for which there were very high barriers to change, all the way to the other side of the matrix—behaviors that were unimportant, easy to change. What we tried to do was target those issues that fell toward the most important but most changeable part of the matrix.

Hughes: I saw lists of activities, mainly sexual activities, as I remember, with figures written in after them.

Bolan: Yes, that was our scoring system.

Hughes: The methodology was dictated by the PRECEDE model?

Bolan: Yes. And we valued them subjectively. We just said, "On a scale of--" I don't remember what the scale was, one to four or something like that--"what weighting do we give this particular issue?" And we would discuss it, come to a consensus, and [give it] a score.

Hughes: The idea was to tailor the guidelines to fit these parameters?

Bolan: Yes, those behaviors that were important and had some hope of being changed.

By the time we had gotten about two-thirds or three-quarters of the way through this process, the results of Larry Bye's telephone survey were finished and available. They helped us to finish this approach. Actually, it was probably a quarter of the way into it that we had these data.

Hughes: That survey covered how many?

Bolan: Five hundred.

Hughes: Five hundred self-identified homosexual or bisexual men was the survey group.
Bolan: Yes. And it is the first ever study of any sort that broadly surveyed the [gay] population. It was the first time that anybody was ever able to make a guess at what the size of the gay population in San Francisco was. It was an extremely important tool. So it helped to inform our discussions, but it also sparked another parallel process within the AIDS Foundation.

The person at the AIDS Foundation who was in charge of this from a staff standpoint was Sam Puckett. Sam was an attorney who was on disability, I believe it was with HIV, although he never discussed it specifically. Very smart man, very able to cut through a lot of wide-ranging discussion and get to the meat of the issue very quickly. Sam didn't have a whole lot of patience with the approach that I was taking, because it was kind of slow and ponderous. He was more of the opinion that we could hardly do wrong by taking a couple of simple messages and putting an emphasis on those, and just going out and plastering them all over the place.

So he took the Research and Decisions Corporation survey, got an advertising company--it's referenced in one of these documents; I don't remember what the name of the company was. But it's in my PRECEDE paper that I presented at the first AIDS conference in '85. They received the Research and Decisions telephone survey and our final analysis together, and I don't have to this day any real knowledge of how they used them both, whether they didn't use our analysis at all, or what.

An Algorithm for Targeting Intervention Points

Bolan: One of the things that I did on my own after the analysis was complete-- I was up at the Russian River staying at one of my patients' cottages. He let my lover and me have it for a weekend. I was sifting through all of this stuff, and I came up with a sexual behavior algorithm. I guess as I was doing it, I thought, Gee, this might be an interesting tool as a roadmap to try and figure out where to target certain interventions. And the algorithm started at the top, from the first inkling of being sexual, all the way down through all the various possible permutations and combinations--meeting a willing partner, or not meeting a willing partner and postponing the activity, going off and being sexual by yourself, or engaging someone else.

And then as it got down further and further on the page, it got a little bit more complicated, because once you meet a potential partner, there is negotiation for what's going to
happen. And that negotiation is nonverbal most of the time. So I mapped out all those possibilities—if there were any words spoken, I put those in as possibilities as well.

After I was finished putting down what I thought were all the various possibilities, then I went back through and put my guesstimate as to how likely an intervention would be effective at a particular point. So I handed that over along with all the other materials, and as I say, I have no idea whether they said, "What the hell is this?" and threw it in the wastebasket or not. I've had this nagging suspicion that's that exactly what they did with it. But as a result of whatever they did do, they came out with the AIDS Foundation's first series of [guidelines]--

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Bolan: The contribution of the PRECEDE model, such that it was a contribution, was a really very small monetary part of it, because I paid the consultants something like fifty bucks apiece in 1984 dollars. That is probably equivalent to twice as much today. I mean, it was a token amount. But the majority of whatever funding we got went into the ad campaign with the ad agency.

Hughes: What were those ads like?

Bolan: As I say, I don't remember the specific ads and what the messages were.

Hughes: Are we talking about the Stop AIDS campaign?

Bolan: No, this is not Stop AIDS. This is pretty much a billboard, fliers, matchbook cover, type of thing. I don't remember whether there were any PSAs [public service announcements] on TV that were part of this or not. Oh, and there were also posters in the buses. That was a big deal.

Hughes: Did you try to assess how effective these procedures were?

Bolan: No. We had no money to do effectiveness analysis, and that was one of the reasons that I wrote to Jim Mason at the CDC. One of the reasons that I argued for the PRECEDE model was, as I say:

The PRECEDE model as described by Larry Green, Marshall et al. is, I think, the appropriate tool to critically examine popular biases, weigh them, draw out more incisive observations, and then select from them the most likely determinants of at risk behaviors in different subgroups, rank them in terms of
changeability and importance[,] and then
target messages through appropriate media in a
preplanned direction. Done in this way, such
programs are evaluable and hence exportable to
other locales (at this point, my strong bias
is that communities with differing disease
prevalence and different acceptance of
homosexuality will have different social and
health priorities.\(^1\)

Funding Requests

Bolan: So my message here is that, we're trying to be innovative and
creative and sophisticated, but unless some effort is put into
evaluating what we do, we're not going to make any forward
progress. So I was pleading for more federal dollars to be put in
education, part of which would be used to help evaluate programs
that were developed.

Hughes: What was the reaction?

Bolan: I think Mason wrote me--I'm surprised I don't have the response.
Because everybody that I've ever written to at the CDC or the FDA
has always answered me. It doesn't appear that any of them have
any secretaries, and it's always about four months after I write.
[laughter] And that hasn't changed a bit. I wrote a letter of
support to the outgoing surgeon general, Joycelyn Elders, after
she was unceremoniously dumped. I said, "I thought that what you
did was very courageous and very appropriate. You can't do good
health education by talking mumbo jumbo and by using code
language. You've got to tell it like it is." And I cited my
earlier experience with the AIDS Foundation, sent it off to her,
and about four months later I received a very nice response that
was typed by her. [laughs]

Hughes: Well, whether you got a letter or not remains to be seen, but you
didn't get the money, as far as I can figure out.

Bolan: Right! [laughs]

\(^1\) Bolan to James O. Mason, August 1, 1984 (Bolan papers, UCSF
Library).
Organizational Changes and Problems

Hughes: Let's talk about some of the internal problems of the AIDS Foundation, or is there something more pressing?

Bolan: No, I think that would be fine. From my perspective, the biggest challenges with the AIDS Foundation can be summarized as follows. It started off as a volunteer organization in April of '82. When I took over the reins in June of '83, we submitted our first budget to the city, and there's a financial report someplace in these papers that tells exactly what we spent our first $60,000 grant on for a year's worth of operation. But as you can imagine, it was pretty low salaries and a pretty skimpy social service budget.

Hughes: For how many people?

Bolan: I think we had five people. And we were trying to provide social services at the same time, and trying to develop some education messages. We went from an organization of that size in June of 1983 to an organization that had a budget of $2 million when I left in January of '86, so we were an organization that very rapidly grew from nothing to a $2 million budget. And over that time, we grew from a volunteer organization--folks who had a lot of enthusiasm but not much training or background in their particular jobs--to a financial position where we could afford to hire people more appropriately qualified for their positions. But that process took time.

Superimposed upon that growth and those economic constraints and realities was the governance structure. It was and is a nonprofit organization, and the board of directors is a noncompensated board. When the organization was first formed, those members, like myself and the others, had more expertise and wisdom in administration and management of our various businesses and concerns than did our staff. So it was natural for the board to be the policy-makers and the people who decided day-to-day activities. Well, from the standpoint of a board of directors, that's an absolutely disastrous and self-defeating structure. But that was the energy that we had, the expertise that we had, and we had to use it that way.

So at some point, the board had to make a transition, and I think that probably my best contribution to the early growth of the organization is that I shepherded it through the transition from a virtually zero-budget organization peopled with board of directors who directed the organization to a board of directors that governed rather than directed, that set broad policy but
didn't get involved with the day-to-day organization, and that was involved primarily in fundraising. It made a transition to an appropriate kind of board.

That's the background, and superimposed on that are all the daily realities of things that we had to deal with, such as preparing budgets and budget accountability to the AIDS office of DPH [San Francisco Department of Public Health]. Frustrations that arose in that area were primarily driven by the fact that none of us really had any expertise, even those of us who were business people. What did we know about contracting with a city government for health services? Nothing.

The biggest single frustration that I had was that every granting organization, whether it was the city or whether it was the state, or even whether it was federal dollars later on, allowed for such a minuscule administrative overhead that that fact almost assured that there would be insufficient funds to get the expertise to administer those grants properly and to do the proper reporting, or to even find the help to learn how to do that. There was a nonprofit organization--I can't remember the name of it now--whose sole function was to help nonprofit organizations learn how to govern rather than to direct, that taught the board of directors what their proper role should be, that taught people how to write grants for areas that they felt deficient in, and so forth. They were very helpful to us in acquiring some of these tools.

But the frustration that we were going through, we were not alone in. Other community organizations were going through the same thing. The partnering between the Department of Public Health and community organizations--this outsourcing of activities that the department didn't have the expertise to do to community-based organizations was a principle that the DPH began to use very early on, and not only in AIDS care but in other areas of DPH activities. They found it to be a very effective model, but there were significant problems with it.

There were other frustrations and internal problems that I think are pretty typical of any community-based organization--strongly held opinions about ways to do things, and personality conflicts, and organizational politics, and stuff like that. Another important thing typical of AIDS was emergency issues that the organization had to deal with, that seemed to come up almost on a weekly basis and that would draw the attention of the entire organization to this one issue. We would drop everything else that we were doing, focus on the crisis for a while until the next one came along. Managing for crisis, crisis management. We were definitely in a stage of crisis management, and I even coined a
different term for it that I still use to this day, which is management by the shitstorm of the week. [laughter]

San Francisco Model of Comprehensive AIDS Care

Hughes: Is outsourcing a common procedure of a local department of health?

Bolan: I don't know whether it is around the country or not.

Hughes: I ask that because I'm thinking of my next question, which is, isn't outsourcing a basis for the San Francisco model of comprehensive AIDS care, namely, if you had a health department that felt it should be providing all these services on its own, then you wouldn't have a San Francisco model, would you?

Bolan: I think you're right; I think that is the basis for the San Francisco model. And I think the San Francisco model began to limp and burst at the seams and wheeze from the lungs 'round about 19--oh, I don't know, probably '90--with so many community-based organizations that were beginning to provide overlapping services.

Hughes: Yes, and fishing from more or less the same pots, too.

Bolan: Yes, competing with each other. I don't know what point that became really a problem. Maybe about '90. But I think it's a very good model, because it has as its core assumption that to really deliver particular services to a subpopulation that's identified by certain values and beliefs, you must select messengers and planners and administrators from that population, and that what better way to do it than to empower the community to own part of the problem and own the solution? It's a brilliant model. I think the only thing that was lacking was a sufficiently tight administrative overhead to make sure that this duplication didn't occur, and I don't know why that didn't happen.

The Federal Government and AIDS Education

The Centers for Disease Control

Hughes: On September 19, you wrote to Marshall Kreuter, who was director of health education at the CDC. I quote you: "I am frustrated by
the lack of federal monies to support this most important aspect of AIDS prevention—education."

In October, 1984, you reported to the board of directors of the AIDS Foundation on a recent trip that you had taken to the CDC to talk about AIDS education. The minutes report, "It seems that CDC is somewhat dragging their feet on fiscal commitment to educational programs. There is no clear feeling of what CDC will do from this point."

Bolan: Yes, I remember that meeting. It was probably about a week before the first time that the federal government ever shut down. I was at the CDC for these meetings, and everybody went home. [laughter] I'm sitting here, "What the hell's going on? I came all the way here from San Francisco and you people are going home? Give me a break!"

Hughes: You must have had some feedback that the CDC was not going to actively support an AIDS education campaign.

Bolan: Yes. At this point, I began to lose faith in the CDC as far as education was concerned. Sometime after that, probably in '85, the CDC began to recruit me to come and join the CDC in the Division of Health Education, Marshall Kreuter's division. I went and talked to Dr. Willard Cates, Marshall, Rich Needle—I don't remember whether I met with Jim Curran that time or not—about the idea of bringing me on board with the CDC to be part of or head up the AIDS behavioral or health education team. I wasn't being asked to head it up, I don't think, but to be an important part of it.

Hughes: Obviously, you considered the offer, or you wouldn't have gone to Atlanta.

Bolan: Oh, I very seriously considered it; I don't know why eventually it didn't happen.

Hughes: You had said yes?

Bolan: No, I hadn't said yes. We had got to the point of salary negotiations, and I don't know whether I was asking for too high of a salary because I was coming from private practice.

1 Bolan to Marshall Kreuter, Ph.D., September 19, 1984 (Bolan papers, UCSF Library).

2 Minutes, San Francisco AIDS Foundation Board of Directors meeting, October 11, 1984 (Bolan papers, UCSF Library).
More likely, it was my firm and outspoken position that any health education would have to contain very specific sexual language, and had to be couched in gay-positive and sex-positive terms. Otherwise, I ain't coming. And that's probably what did it, although I never really found out for sure.

**Surgeon General Koop's AIDS Brochure**

Hughes: I'm trying to think when [C. Everett] Koop's leaflet came out. Was that 1986?

Bolan: Talking about condoms?

Hughes: Yes, which was "revolutionary," because it was more sexually explicit than most government publications.

Bolan: No, it was probably late '85, because I left the AIDS Foundation in January of '86, and I was still at the AIDS Foundation when Koop's brochure was distributed. I remember going up and talking to Dr. Koop at the reception that we had for him at Fisherman's Wharf, Alioto's Restaurant or wherever the hell it was, and feeling very proud in telling him that the San Francisco AIDS Foundation commissioned and funded the study that Marc Conant did to demonstrate that condoms would in fact contain HIV and prevent its transmission. So that was in late '85 that he came out with that. Well, I'm not sure that that's when the brochure came out, but at least he was making public statements to that effect. Is that the brochure that was sent out nationally to every family?

Hughes: That's the one I'm thinking of.

Bolan: That may have happened later. I remember at the time thinking, It's a nice gesture, but it is a colossal waste of money, a colossal dilution, a large amount of money for a single, one-time message targeted to everybody. I don't know how much money it cost, but I was appalled at the planning that went into that; it was really misguided.

**The CDC Division of Health Education**

Hughes: Couldn't Kreuter's division at the CDC supplied Koop with information?
Bolan: Well, you've got to understand how the federal government works. The surgeon general is head of the U.S. Public Health Service. The Centers for Disease Control is a totally separate organization. The Centers for Disease Control is not under the authority of the surgeon general. So there was always a little bit of the right hand and the left hand.

Hughes: Well, I know that there has historically been tension between the CDC and NIH.

Bolan: Yes, and that's again another case in point. But Kreuter was also battling another issue in that, while he was the director of the Division of Health Education, I don't think his boss was interested in HIV. The Division of Health Education was in the Center for Health Promotion. The Centers for Disease Control is called Centers because there are many of them, and one is the Center for Health Promotion, I think it is. The director of the center, I don't remember the man's name, but his focus and mission in life was alcohol--alcohol abuse and alcohol diseases and everything that arises from alcohol use and abuse. So he was not terribly interested in HIV. I talked to the man. He did all the right nodding and smiling, but nothing else happened after that.

Marshall left the CDC not too long after that. I don't know exactly why, but I wouldn't be surprised if it wasn't partly due to some frustration, and also, somewhat different career goals on his part. I'm not sure how fully invested in all this Marshall was either, but he was a good soldier. He showed up, worked hard, seemed to put his heart into it.

Opposing Views on Behavior Modification

Hughes: Well, let's turn to the letter from Conant in which he criticizes the proposal that the AIDS Foundation has drafted for the San Francisco health department. One of his criticisms is, "...much too narrow and the budget is clearly too low." You have the letter there?

Bolan: [tape interruption] I have the copy here, but I don't think that Marcus sent me a copy of it. Yes, I'm not copied on this, which I think is an interesting comment all by itself. Off tape, you

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1 Marcus Conant to Mervyn Silverman, August 27, 1984 (Bolan papers, folder: San Francisco AIDS Foundation: High Risk Education Project Correspondence, Bolan papers, UCSF Library).
asked if Marcus was a continued force in HIV at this point, which is August, September, 1984, and you suspected that there might have been some tension developing between him and the AIDS Foundation. That's exactly right, and I think that the tensions are severalfold.

First of all, remember, he asked me to chair what he thought was going to be a local San Francisco chapter of a national foundation [Kaposi's Sarcoma Research and Education foundation]. For various and sundry reasons, that national organization never took hold. So he found himself sort of on a side track, dead-ended, from the decision-making and the policies and procedures of the foundation that he started. I think that was a source of frustration to him. That was one factor.

Another factor was something I think I alluded to yesterday or the day before, which was Marcus' approach. I don't remember Marcus' attitudes very much, but his statements were often couched in alarmist terms. Not that it was inappropriate to be alarmist, because [HIV] was a horrible thing, it was obvious that it was a horrible thing, and not a lot of the right people were paying attention in the proper way. But his alarmist beliefs or his alarmist methods of delivering his ideas spilled over into what his beliefs were about education. My recollection of those beliefs were, Hit'em hard with the most awful, gruesome if necessary, information, and keep hammering those messages of how terrible this is, how terrible this is, you don't want to get this disease.¹

On the other hand, I came from a totally different perspective, as I think I've talked about it all the way through our discussions here, which is a belief that if you want to deliver a health message that you expect or hope to be heard and acted upon in some sort of a manner, you can't scare your intended audience away, either physically, or scare them to the point that they don't even hear what you're saying, or if they hear it, it frightens them so much that they run in an opposite direction of where you want them to run.

I arrived at that belief on the basis of my several years of experience at this point with trying to do health education in sexually active gay men, both with the NCGSTDS and later on in BAPHR. I was of that opinion because that is what the health education literature supported. There was one meeting that I remember very well in the back room of the AIDS Foundation on 10th

¹ The reader may wish to refer to Conant's oral history in the AIDS physicians series.
Street. Marcus, Dick Pabich I think was there, I think Phil Conway, who was Marcus' executive director for the National Foundation, was there, and I, and probably Rick Crane and a few others from the AIDS Foundation.

Hughes: And the year?

Bolan: This would have been early '84, probably before this letter that he wrote to Silverman. As I'm saying that, another thing pops into my head. It's possible that that meeting that I'm remembering right now happened after this letter. It may be that Merv asked me to meet with Marc because Marc was unhappy, and Merv wanted to see if we could kiss and make up. That's entirely possible. I don't know for sure.

Hughes: That also sounds like Silverman, the consensus-builder.

Bolan: Yes, it does. And if that's the way that it happened, then we would have come to this meeting with fairly hardened positions. I recall the meeting as collegial but from a position of two very hardened viewpoints.

Hughes: People didn't change their viewpoints as a result of the meeting.

Bolan: Yes. Except that Marcus didn't know that I had been taking a scholarly approach to this, that I had been searching the medical literature, that I wasn't flying by the seat of my pants. It may be a little bit overreaching to say that I might have embarrassed him, because he was an academician, and caught him with his scholarly pants down, as it were. I don't know whether that's true or not. But I said, "Look, Marc." I just played that tape that I just played you, and I said, "There is evidence in the literature that scare tactics don't work, and in fact, there are plenty of studies that document that when you use scare techniques, particularly with things like smoking that have terrible outcomes, that what happens is that you drive people into more risky behavior." [beeper interruption]

So we both had these hardened positions, and I quoted him these studies that defended my point and refuted the scare-tactic approach. As I recall, that pretty much ended the controversy, or at least his resistance. I made it fairly clear to him that there just wasn't going to be a campaign that was based upon fear tactics. I think that that was really the basis of his concern about narrowness.

Now, as to Marcus's concern about insufficient funding, I don't recall whether we discussed that or not. But I don't remember that there was a whole lot of additional friction or
argument or dialogue about the direction of the ad campaign. He
may well have had other pointed criticisms of it and its seeming
lack of effectiveness, and where were the messages, and where's
the behavior change, but I just don't remember them.

I do remember that toward the end of '84, that the rates of
rectal gonorrhea in San Francisco were beginning to plummet
significantly. In fact, I remember calling on Hunter Handsfield
at the Seattle Department of Public Health--he was the director of
public health there--to help with a little statistical analysis on
the phone, showing whether or not the declines in the interval in
which these changes were happening was statistically significant.

Hughes: You were using rectal gonorrhea as an index for the effectiveness
of your campaign?

Bolan: Yes, as an index of unsafe behaviors, and as also an index for the
successfulness of all the educational efforts. Hunter graciously
did a little phone consult with us and provided that extra
assurance that yes, this did seem to be proper. I think at that
point, we were able to feel a lot more confident that our efforts
were effective.

Hughes: Well, is that enough coverage of risk reduction efforts?

The Stop AIDS Project

Bolan: It's important to note that the Stop AIDS project was developed as
a result of the Research and Decisions Corporation telephone
survey. Larry Bye started the Project after watching the focus
groups that he assembled to test the messages that the advertising
campaign proposed to use. Larry said, "Gee, these focus groups
seem to be a potent educational tool in and of themselves. Let's
model the Stop AIDS project after this idea, and let's deputize
people to be group leaders within the group of discussants." That
was another very important outreach in the community.¹

¹ A few paragraphs were moved for better chronology to a position
earlier in the transcripts.
Collaboration Between Community and University Physicians

The San Francisco County Community Consortium on AIDS

Hughes: Well, in January, 1983, as far as I know, there was no formal research on AIDS going on in San Francisco. The first NIH grant didn't come through until, I think, April of that year. The San Francisco General group was one of the beneficiaries, and I believe there was some correspondence between BAPHR and Paul Volberding or one of the people at the General about somehow contributing to that study. Did that happen?

Bolan: Well, no, it ultimately didn't happen. I know that the Community Consortium that Don Abrams' formed several years later was really an outgrowth of the belief that community physicians had much to offer and a great desire to be part of the discovery process, and part of a process that could bring interesting research questions to the fore and answer questions that couldn't be answered in another venue. But at this early point, I think the NIH rightfully looked at established academic institutions as the most efficient participants.

Hughes: Were academic institutions, including UCSF, looking for opportunities to collaborate with community physicians?

Bolan: Well, I guess you'd have to look at Donald's recollections for how the consortium came to be. I think originally it started as a sort of information-sharing group, as a network. And maybe initially, it was conceived as a way of providing access to studies that were being done in San Francisco General by informing the clinicians in the community what the university was doing. I don't really remember what the founding principles were.

Hughes: The consortium comes along somewhat later than what we're talking about here.

Bolan: Yes, it does. But I believe that the consortium, if not conceived by Donald, was certainly championed by him and embraced by him enthusiastically. That's his baby; that's his claim to fame.

Hughes: The consortium grew out of a meeting that was prompted, I believe, by former Mayor Dianne Feinstein's concerns that the number of AIDS cases were going to overwhelm San Francisco hospitals,

1 For more on the San Francisco AIDS-Community Consortium, see the oral history in this series with Donald Abrams.
particularly San Francisco General, a county-supported institution. She contacted Volberding who met with community providers of AIDS care, and then handed the torch to Donald Abrams.¹

Bolan: Oh, that makes perfect sense to me, because I remember in the early days when each of us in the community had few patients, that we would refer our patients that had Kaposi's sarcoma to the KS Clinic at the General,² and they would then transfer their entire care over to them. So what was being set up was a system whereby the sickest of the sick and the complicated cases, as they began to evolve, would all be referred to the General.

Tensions

Hughes: Was that all right with community physicians?

Bolan: No, it wasn't all right. It wasn't all right because we didn't want to lose our patients, and it wasn't all right from the city's, from Dianne's perspective; it wasn't all right because, Jesus, if all the community physicians refer all their patients into the General, we're going to be overloaded. Let the community physicians and the community hospitals share the burden here.

So that makes perfectly good sense, that's how the Consortium was started. If that's the first historical evidence of the germinating idea, then that's probably exactly what sparked it. I don't think I knew that. I came to understand later on that really we had to spread the burden here.

Hughes: Had there been other instances of academic researchers and community physicians collaborating?

Bolan: There has always been an attempt to do that. In every university setting, you've got this concept of "town and gown." Those terms are referred to in other contexts than medical, but in the medical context, what they mean is that those in the university setting always have great intentions for collaborating with their community physician partners and feed back information to them,

¹ See Abrams's oral history in the AIDS physicians series for further details.

² The KS Clinic, founded by Marcus Conant in 1981, was at UCSF; the AIDS Clinic, founded in 1983, was at the General.
and educate them about research protocols that are going on. They always have great intentions of doing that, and going out and giving lectures and grand rounds to help to make a relationship, but in reality, most of the time it tends to be frustrated and a one-way street. If a community physician refers a patient into an academic center, rarely do they get back timely information. Frequently what happens is that, rather than working collaboratively back and forth with the referring physician, whoever gets the patient will then refer the patient on to somebody else in the university, and pretty soon the patient starts spinning and gyrating among the departments, and you never see the patient again. That's the usual event.

Hughes: Hence, were you and your colleagues reluctant to refer patients to UC?

Bolan: Well, initially, we found it a necessity, because nobody else had the cumulative expertise to know exactly what to do with these patients. So we referred them for that reason. But at some point, I think we all began to say, "Wait a minute. This doesn't feel comfortable. This feels like a record that I've played before. I've played this game before, and I didn't like the way it came out."

And the other part of it is that obviously, if we keep referring the difficult patients out, then we don't develop our own expertise. It's a self-perpetuating prophesy.

Hughes: I saw some correspondence between you and David Ostrow, who as you know was the director of research at the Howard Brown Memorial Clinic in Chicago. You were talking about establishing a national AIDS case-finding and collaborative research network. This was in May, 1983.

Bolan: Ah, yes. That was one of David's brainchildren.

Hughes: What happened to it?

Bolan: Well, as with many of David's brainchildren, it didn't grow up to be an adult. [laughs] David is a very bright, energetic individual, and I don't really remember why that particular thing didn't get off the ground. I suspect because he wasn't able to find funding for it.¹

¹ A portion of the text was moved, for better chronology, to a position earlier in the transcripts.
Hughes: One last question. What would you say is your greatest contribution to HIV?

Bolan: [pause] Persistence. Showing up. And an attempt to approach this disease from a multifaceted approach: from an educational approach, from a social activism approach, and community organizational approach, and finally from a medical approach. That's it. Thank you for asking that question; no one has ever asked me that before.

Hughes: That's a wonderful answer. I thank you.
Volume III

William F. Owen, Jr., M.D.
AIDS CLINICAL PRACTICE IN THE PRIVATE SECTOR

Interviews Conducted by
Sally Smith Hughes, Ph.D.
in 1996

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INTERVIEW WITH WILLIAM F. OWEN, JR. M.D.

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Bill Owen, an internist in private practice, was interviewed for the AIDS oral history series because of his early and prominent role in the care of AIDS patients in San Francisco. In fact, like some of his medical colleagues interviewed for this series, he has realized in retrospect that he was treating patients with symptoms of AIDS before the disease was recognized, let alone defined and explained. Owen describes two cases in gay men, one in the late 1970s of a possible HIV-related encephalopathy affecting the brain, and another of generalized lymphadenopathy or swollen lymph glands. Neither he nor other medical specialists were able to arrive at a diagnosis, despite exhaustive physical examinations and a battery of laboratory tests.

The epitome of the competent and compassionate clinician, Owen in the oral history comments on many aspects of managing a busy AIDS practice, with the emphasis, as usual in this series, on the initial period when San Francisco was a— if not the— leader in comprehensive AIDS clinical care. The particular strength of the oral history is in the detailed picture it presents of early clinical treatment of AIDS. Owen also remarks on expanded drug access, a movement aimed at making experimental AIDS drugs more quickly available to patients. He describes his initial opposition to the HIV antibody test as long as rational treatment for AIDS did not exist, and the complete reversal of his position with the arrival of AZT as the first effective drug treatment for AIDS.

Oral History Process

Two interviews were conducted late in the day on March 27 and April 23, 1996, in Owen's office at his busy private medical practice at Davies Medical Center in San Francisco. Friendly and seemingly relaxed despite a long and taxing workday, Owen talked readily about his experience of the early years of the epidemic. The lightly edited transcripts were sent to Owen who made a very few changes.

The two interviews reflect the views of a fine physician who continues in the demanding work of providing both state-of-the-art clinical care and holistic and humane support for his many patients with HIV/AIDS. Asked what his long involvement in the epidemic has meant to him, he responded:

I think I've made an important contribution, maybe not in terms of being involved in major research projects, but I think in terms of being able to be just a good physician for my patients. I think that I've helped them through the
process of their lives and through the dying process. I think I've done a good job in that respect.

It's taught me a lot, too, about what it means to live and what it means to die. The courage of many of our patients has given me a lot more courage in terms of facing life and facing death. I always had fear: how would I face this in my own life? And I don't have that fear any more. I feel that I've been able to assimilate some of the courage that my patients have shown.

Sally Smith Hughes, Ph.D.
Research Historian and Principal Editor

February 2000
Regional Oral History Office
The Bancroft Library
University of California, Berkeley
I UPBRINGING AND EDUCATION

[Interview 1: March 27, 1996]##

High School and University

Hughes: Dr. Owen, I want to go back to where you were born and educated, and to hear about your career up until the point of your recognition of the AIDS epidemic.

Owen: I was born [February 24, 1949] in Philadelphia, Pennsylvania, and went to elementary school there. Then I went to Central High School, which at that time was all male and the second oldest academic high school in the United States, second after Boston Latin. It was some time before that that I decided I would go into medicine. So I had an interest and a focus even then in doing what I needed to do to go to medical school.

Hughes: What prompted you to choose medicine?

Owen: I was inspired by my pediatrician, who was this very nice gentleman by the name of James Bowman. He used to ride around in a Volkswagen Beetle making his house calls. So at that time, I wanted to go into pediatrics, and ended up not doing that but treating many young adults, so I probably went into the closest thing to pediatrics.

Medical School and Residency

Hughes: What happened after high school?

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## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.
Owen: I stayed in Philadelphia. I lived at home, and went to college at Temple University [1965-1969], where I received a scholarship and majored in chemistry. I graduated with honors, and after that went to medical school at Temple University School of Medicine [1969-1973].

Hughes: Why chemistry?

Owen: I was interested in science, in addition to medicine, so I thought that I wanted to major in science. Ever since I was a little kid, I had a chemistry set, and chemistry was something that I had maintained an interest in, so I majored in that.

Hughes: Has your major served you well in your practice?

Owen: Well, knowing the biochemistry of how the newer drugs work is extremely important, and basic human biochemistry is obviously very important for your knowledge of growth and development and metabolism. So yes, I think it has been useful. Certainly I don't remember a lot of the details of physical chemistry. Organic and biochemistry were useful.

Hughes: And your residency training? Was that what happened next?

Owen: We used to call the first year of residency training internship back then, and I decided there had to be life beyond Philadelphia. I ended up looking all around the country. It was the first time I had actually left the East and traveled around. But I eventually settled on a place that was not too far from Philadelphia; it was only a five-hour drive away. It was a place which is now called Baystate Medical Center in Springfield, Massachusetts. At that time it was called Springfield Hospital Medical Center.

The reason I selected that residency program was that it was a very primary care-based program. At that time, it was very unusual for internal medicine to be very interested in primary care. Most times, people were expected to go off and do a subspecialty, go into cardiology or endocrinology or whatever. And most of the programs were based in academic medical centers at university centers where primary care was really looked down upon.

But at Springfield, they maintained a whole cadre of professors who were actually clinical professors at Tufts University School of Medicine at Boston, but who were full-time at Springfield. They were devoted to teaching the interns and residents, so it was a very good learning experience. And we could also learn from the attending physicians as well, the
private practice physicians, but we had this additional almost academic focus without necessarily being in an academic center.

Hughes: Why were you drawn to primary care?

Owen: Well, by two experiences. My first experience was an externship that I did between my sophomore and junior year in medical school. That was at a place at that time called Sacred Heart Hospital. It's now part of a larger entity called Lehigh Valley Medical Center. I did it with a family practitioner, followed him in his office, and spent time in the hospital making rounds with him. It was just a very positive experience.

The first rotation that I did right after I returned to medical school that fall [1971] was in internal medicine, at Episcopal Hospital, which was in a working-class and poor area of Philadelphia. Now, there was a fairly large minority population there as well. It was a place where as medical students we were allowed to do a lot more than we would have been at a university medical center in terms of actually participating in the care. Under the supervision of the residents we were writing the orders, learning procedures, and feeling closer to the patients than we would perhaps have in other settings.

So both of those were very positive experiences and fed my interest in primary care, and I think that's when I moved away from pediatrics and more toward internal medicine.

Hughes: Was there a little stigma about being associated with primary care?

Owen: Well, there was, yes. Primary care was just not a focus at all in the academic world. People just didn't do that. There were no departments of general internal medicine; there were no departments of family practice.

Hughes: So by deciding on primary care, you ipso facto made the decision against academic medicine, did you not?

Owen: Yes.

Hughes: Was that deliberate on your part?

Owen: Well, yes. It wasn't that I would have rejected an academic medical center entirely, but I felt that the direction that I wanted to go was really more toward primary care and being able to treat patients in practice.

Hughes: Yes, then what?
Owen: After my year of internship at Springfield Hospital I did my residency there. By that time it had changed its name to the Medical Center of Western Massachusetts. I spent my last two years there, which would be now called the postgraduate year two and postgraduate year three, and then I took and passed my boards in internal medicine in 1976.

I then decided that I wasn't ready to go out into clinical practice. At that time, there was a real push nationally to get more people involved in emergency medicine, and I thought, Well, I could probably use my primary care skills there and learn something a little bit more about some surgical things I didn't learn in my internal medicine program.

Hughes: What was your hesitation about going straight into practice?

Owen: I didn't feel at that time that I was quite ready to settle down. The only place I knew at that point was right in the area of Springfield or the immediate suburbs. I could have gone into practice there. I wasn't really sure that that was the geographic area that I wanted to be in.

_Fellowship in Emergency Medicine, UCSF_

Owen: I was looking at job ads but also at academic ads, and I saw an ad in _The New England Journal of Medicine_ for a fellowship in emergency medicine at the University of California, San Francisco. I thought, Well, gee, that would be a really interesting program and a very nice location. It was just around the time that my own stirrings of coming out as a gay man were happening as well, so I thought also that San Francisco would probably be a nice place to be as a gay person. I'm not sure that I felt that consciously, but I think subliminally I did. I remember reading in _Time_ magazine stories about the gay movement in San Francisco even back then.

So then I was accepted into the program and moved out to San Francisco [1976] in my Volkswagen Beetle which I had bought, emulating my pediatrician. [laughter] With the help of my younger sister Deborah Jean Owen, who emulated me and started medical school that year, in 1976. She's now the medical director of the San Francisco Fire Department.

Hughes: So you've both ended up in San Francisco.

Owen: Yes, our whole family.
That was a two-year program in emergency medicine, and we rotated around various facilities. It was based at Moffitt Hospital at the University of California, San Francisco, but we also did rotations through San Francisco General Hospital [SFGH], Highland Hospital in Oakland, and Oakland Children's Hospital. Those were the major facilities. Also for specialty things, we could rotate outside, so I did a month back in Philadelphia at Wills Eye Hospital for ophthalmology.

Hughes: Did you overlap with Connie Wofsy? She had a stint in emergency medicine at SFGH.

Owen: Yes, Connie was one of the two co-directors. She was the medical director, and there was a surgeon who was a director too. That's when I met Connie Wofsy, way before the AIDS epidemic. She knows me now to say hi; I'm not sure that she even remembers that I was there back then. I was just one of these people rotating through the emergency room among all the other hundreds of residents and medical students.

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1 See the oral history with Constance B. Wofsy, M.D., in the AIDS physicians series.
II THE AIDS EPIDEMIC

An Early "AIDS" Case, Late 1977 or Early 1978

Hughes: Did you see anything in those years that you later look back on as possible AIDS cases?

Owen: Yes, I did. I had a very moving experience. I was doing a cardiology rotation through Moffitt in 1977 or '78, and we were asked to see a young man in consultation who was on the neurology service. He had been admitted. He was a patient of one of the physicians, Tom Ainsworth, who practiced in the Castro back then. He had originally moved to San Francisco from Hawaii. All of a sudden he was found at home in a coma. He was admitted by his physician to Davies Medical Center right here in San Francisco. They did all kinds of tests here, couldn't figure out what was going on. His parents, who were back in Hawaii, insisted that he be transferred to the mecca, which was UCSF.

So he was transferred to the neurology service there. Well, they also did every kind of test available then. They did CT [computerized tomography] scans. I think MRIs [magnetic resonance imaging scans] might have just been coming into their own. I can't remember if that was done. But they did spinal taps and EEGs [electroencephalograms] and everything imaginable. They couldn't figure out what was going on. They even had, one day I was there, the head of neurology, Dr. Robert Fisher, go over the patient physically. [He] went over all the labs reports, and could not determine what was happening.

We in the cardiology team were asked to see the patient because he had a slightly abnormal [cardiac] rhythm, I believe. That certainly was the least of his problems. He died, unfortunately, after that. I left the service before he expired. But he never did come out of coma, and retrospectively, it appears that he had some type of HIV-related encephalopathy. Whether it was that or PML [progressive multifocal leukoencephalopathy] or
perhaps one of the opportunistic infections that was just missed, we don't know.

Years later, I bumped into his primary care physician, Dr. Tom Ainsworth, who has since retired, and he remembered the case very well too, because it stood out. This must have been one of the first AIDS cases that happened anywhere. We talked about how impotent we felt about not being able to come up with a diagnosis in this case. Even at one of the finest academic centers in the U.S., they still were not able to come up with an answer.

Hughes: You had no inkling at that time that this case might be related to anything else?

Owen: It was just an isolated case, so nobody had the foggiest notion. People weren't even talking about the immune system then. Obviously, if they had done studies of his immune status--I doubt that they were even available then--they would have perhaps gotten a clue about what was happening. But of course, that wasn't conceived of.

Hughes: What year was that?

Owen: Well, let's see. The cardiology rotation I must have done in the second year of the program, so it would have been in late '77 or early '78.

Hughes: Were T-cell tests available?

Owen: No, I think they knew about their function at that time or were starting to learn about the function, but I don't think they were something that you could very easily obtain commercially. If there was anything, it would have been at a very highly specialized research lab.

Hughes: Herbert Perkins, who at the time was scientific director of San Francisco's Irwin Memorial Blood Bank, told me that Becton Dickinson lent him a prototype cell-sorting machine. The machines were not commercially available yet.

Owen: Imagine if this disease had occurred in the 1950s, before we had any of this technology available. It's quite amazing how much progress we've made.
Sexually Transmitted Diseases in Homosexual Men

Prevalence

Hughes: Do you have anything more to say about your stint in emergency medicine?

Owen: Oh, yes. One of the things that I noticed in San Francisco in the emergency room is that we were seeing large numbers of homosexual men who were coming in with various types of illnesses. Not only the common sexually transmitted diseases which we were seeing--gonorrhea, syphilis, and herpes--but things that I had not even really learned about in medical school or certainly in residency in Springfield, Massachusetts. Parasitic diseases: giardiasis, amoebiasis, shigellosis. And the list grew--hepatitis B; we had a test for that then. Hepatitis that wasn't B; I don't think we even had a test for A then. So you assumed if it wasn't B, it was probably A. We didn't even know about non-A, non-B at that time, which is now mostly hepatitis C and some other types as well. I realized that there was nothing about this in textbooks. There wasn't even anything about it in the medical literature.

After the fellowship [1976-1978], I had a year [1978-1979] when I was the coordinator for the emergency medicine fellowship, and I decided it would be very nice to write a publishable paper about this. So I gathered all the known resources that I could find, articles that had been published about these various processes in gay men, and I put them together in what I think is the first compilation of information about these processes. It was published in 1980 in the Annals of Internal Medicine.¹ It was called, "Sexually transmitted diseases and traumatic problems in homosexual men." And that was the other thing too: we saw some things that were traumatic injuries. [tape interruption]

Owen's Publications on Gay and Lesbian Health Care

Hughes: What was the status of lesbian and gay health care when the epidemic was on the verge of being recognized in 1981?

Owen: Well, there was a lot of denial. Certainly specific problems that affected lesbians and gay men weren't being taught in medical

¹ 92(6):805-808.
schools, and residency programs, and postgraduate training programs. So we published this article, in the hope that maybe we would reach people out there and make them realize that in training, as in clinical practice, they would encounter gay men and lesbians as patients.

The level of care that was provided to gays and lesbians throughout most of the country was really inferior. Here in San Francisco, it was better just because we were dealing with so many—especially as far as gay men were concerned—because physicians were beginning to identify some of the clinical syndromes presented by gay men. But still attitudes were a problem; there were people talking about gay men behind their backs, and the attitudes of medical students and residents who came here from elsewhere in the country was not very positive.

Because of that, I wrote a companion article that appeared in The Annals of Internal Medicine called "The clinical approach to the homosexual patient." I went through some of the questions that physicians need to ask about sexual orientation, ways to ask that are more user-friendly, questions about sexual practices which most physicians even to this day still ignore and which are very important in terms of ascertaining risk for various things, and questions about sexual practices that were being done, especially among gay men, that maybe physicians out there were not aware of that could be asked.

I was also trying to get increased sensitivity to the fact that there are gay people out there, even though many physicians were not aware that they might have gay people in their practice, that in fact there were gay men and lesbians everywhere, and so the hope is that physicians would start asking about this.

Hughes: How were the articles received?
Owen: Well, they were actually very well received. I received requests from medical schools for years and years afterwards, requests for them to reprint it for classes that they had.
Hughes: That must have pleased you.
Owen: Oh, very much. And I'm sure there were many others that probably didn't even ask, [laughs] just copied the articles anyway.
Hughes: You had had no specific training in this area in your education?

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Owen: Oh, no, never. No, only informal training that I picked up in the emergency rooms at UCSF, and learning from people like Connie Wofsy. I remember Connie talking about an epidemic of scarlet fever among gay men. I'd never seen scarlet fever before. So it was more learning from people who had been dealing with these problems for a few months or a couple of years, and were sharing their experience.

The Gay Medical Community in San Francisco

Lesbian and Gay People in Medicine Committee, American Medical Student Association

Hughes: What was there in the way of a gay medical community when you arrived in San Francisco in the mid-seventies?

Owen: Oh, there was really none at all when I arrived here in '76. In 1977, I saw an ad--I think it was in the American Medical News--something to the effect that any gay physician who might be attending the American Medical Association [AMA] meeting, which was to be held in San Francisco, was welcome to attend a reception for gay medical students and gay physicians. And I thought, Well, that looks interesting. I had not come out publicly at all. I had only had one sexual experience. But I thought, Well, I'll write and see what happens.

So I wrote a letter to this young medical student, Paul Paroski who was sponsoring this. He was a student at the State University of New York at Buffalo, and he was active in the American Medical Student Association, AMSA. They had started a Lesbian and Gay People in Medicine Committee.

So anyway, the AMA meeting was held out here in San Francisco in June, 1977, and we had this reception. It was very interesting to meet other people who were gay physicians for the first time, because I had this concept all along that I must be the only gay physician in the world. [laughter] Really! The church teaches that gay people are committing a sin; the legal system at that time taught that we were committing a crime, and in many states it was a crime to engage in homosexual relations; and in the medical community, the attitude was that we were sick. It had been only four years earlier, in 1973, that the American Psychiatric Association removed homosexuality from the DSM [Diagnostic & Statistical Manual] and substituted something else called ego dystonic homosexuality, whatever that is.
So meeting all these people for the first time--some of them were medical students, others were in training like myself at that time, others were in practice--was really an inspiration. Some were in academics; they were professors at the University of California, San Francisco. A lot of the people who came for the first time had a lot of fear associated with it. At that time, the climate was so different.

Hughes: Were you afraid?

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Owen: Oh, yes. Several out-of-towners, including Paul Paroski, Bill Siroty, another medical student from New York, and Jerry Cade, a medical student from Texas who now has a large HIV practice in Las Vegas, were at the meeting, but the rest of us who were at the meeting were primarily people who were in the Bay Area. The Northern Californians decided it would be worthwhile to form a local organization. As I said, The American Medical Student Association started this Lesbian and Gay People in Medicine Committee, but most of the people attending this were not medical students. We were either residents or physicians in practice or in academics, and so we decided it would be nice to form our own organization.

Right at that time, the big story nationally as far as gay people were concerned was Anita Bryant. She was attempting to overturn the ability of gay teachers in Florida to be able to teach. She wanted them to be removed from the classrooms. She called this organization that she started Save Our Children. In reaction to that, a number of groups started right around that time, and a lot of them had 'Human Rights' in their name. So in reaction to Bryant, there was an organization in San Francisco that started called Save Our Human Rights, SOHR.

Hughes: Which was gay?

Owen: Yes, it was--gay and lesbian.

Bay Area Physicians for Human Rights

Foundation

Owen: We [the founders of BAPHR] had debates for months and years about what to call ourselves, and there was a real struggle, because
there were some people in the organization who still felt so threatened about being part of an openly gay organization that they would have left if we had called it Bay Area Gay Physicians or something like that. The decision was made to call it something similar to this Save Our Human Rights, and so the name of the organization was Bay Area Physicians for Human Rights, or BAPHR.

There were seventeen of us who met at that first meeting in July, 1977, at my little apartment on 5th Avenue at the top of the inner Sunset, right around the corner from UCSF, because I lived close by because I was doing my fellowship there. Well, there were some people at that meeting who actually parked three blocks down the hill. Now, this hill is really a killer hill. If you're not in totally perfect shape as a long-distance runner or something, you're dead by the time you reach the top of it.

Well, we had all these people coming up my stairway, looking like they were going to need cardiac resuscitation, because they had parked so far away. They didn't want anyone to see them getting out of their cars and coming into my little apartment up there.

We had that first meeting, seventeen people, and we sat around in a circle in my living room. So that's why I became known as the founder of Bay Area Physicians for Human Rights. Well, I had to do a lot of the legwork. I had to send out notices to people and make calls. But there were really at least seventeen of us who were founders at that first session.

Hughes: What were the goals of that early organization?

Owen: Well, as I mentioned, there was a reaction in the political climate at that time to what was going on with Anita Bryant. We felt that if that would happen there in Florida, that it would quickly spread to California. It would remove the ability of teachers to teach, and then we thought, physicians couldn't be far behind. The ability of gay pediatricians to practice pediatrics, and probably other physicians very shortly thereafter, could be taken away. So that was our first motivation.

Goals

Owen: But very quickly in the organization we talked about goals, and we developed in addition what we called the social action agenda, which was that and other things too. Education was very
important. We realized that a lot of these things that I was seeing in my fellowship program, a lot of the clinical conditions encountered among gay men, for instance, weren't being taught in medical schools. So we thought maybe there was something we could do to address that.

Mutual support we thought was really important. Most of us didn't really know a lot of other gay physicians, and we were so amazed to find seventeen of us there. Little did we know that in just a few more meetings beyond that first one, we would be up to the hundreds and would be crowding huge living rooms in Diamond Heights, not able to fit all the people in, there were so many of us. But at that time, there seemed to be a need to just be able to meet other physicians who were gay.

Hughes: So some of the group's purpose was to provide social support.

Owen: Yes. And then we had a final goal of research. This was a more distant goal, but we thought that maybe there would be something we could do in terms of research about gay and lesbian health, and gay people in general. I think it was kind of nebulous at that time. Of course, the AIDS epidemic wasn't here, so we had no concept about research that could be done in that field. But those were our four foci at that time.

Coming Out as Gay Physicians

Hughes: BAPHR held an annual conference, and I know there was a critical one in June of 1981. Do you remember how many annual conferences there had been to date?

Owen: '77 is when we were founded, and then we didn't come out as an organization for a year. One of the patients of the dermatologist who works in my office had saved in a scrapbook an article that appeared in July of 1978 in the San Francisco Chronicle showing a picture of me--many years younger--and David Kessler, who was and is a professor of psychiatry at UCSF. Dave and I have our beaming faces on page 2 of the Chronicle in an article by Ronald Moskowitz about "Gay doctors come out." And it was done just after we had marched in our first Gay and Lesbian Freedom Day Parade in June of 1978. So it was a year after the [BAPHR] organization was founded.

Of course, we had a lot of trepidation about marching down Market Street with the video cameras going. Those people who were in academics like myself--I was coordinating the UCSF emergency
medicine education program at the time, and Dave who was a professor of psychiatry thought, Gosh, there might be a lot to lose here. But we went ahead and marched anyway, and of course nothing bad happened from it, and in fact, we got a lot of really good comments from gay men and lesbians, and from supportive straight people as well.

Actually, the story in the Chronicle was carried nationally by the wire services, and there was reaction. I remember a funny one: Dr. Voth at the Menninger Clinic in Topeka, Kansas, said something to the effect, "These doctors, they're gay? Doctors can't be gay. They must be just plain nuts!" [laughter] So we felt like wearing signs around that said, "Just plain nuts." [laughter]

Hughes: But no negative repercussions from your colleagues in San Francisco?

Owen: No, none at all that I'm aware of. So we had our public coming-out.

Your question, though, was about the symposia. I would say that probably our first symposium would have been the following year. We planned it to coincide with Gay Freedom Day, so my guess is that it would have been in 1979. It started small, of course, and like these things do, they tend to grow. Then I think we probably had one in '80.

The June 1981 BAPHR Conference

Recognizing Kaposi's Sarcoma in San Francisco

Owen: '81 was the seminal conference, because a few months earlier we had heard these reports. I remember getting a call in early 1981 from a dermatologist downtown, James Groundwater, asking me if I had seen any cases of gay men coming in with these purple lesions on their skin. And I said, "Well, no I haven't. Thanks for telling me. I'll certainly look for that." And he said, "Well, I had one case here in my private practice. There's a doctor in New York, Alvin Friedman-Kien, who's been seeing several of these in his practice. We just don't know what to make of it."

1 See the oral history with James R. Groundwater, M.D. in this series.
At that time, my practice was at St. Luke's Hospital in the Mission District, and I talked to a pulmonary medicine doctor, Dr. Abe Aronow, who was a Ralph K. Davies Medical Center doctor, but he came over to St. Luke's sometimes. He said, "Bill, have you been seeing any cases of unusual pneumonia, like parasitic pneumonia?" And I said, "Gee, no, I haven't." He said, "Well, Myles Lippe"--he's a doctor here at Davies--"just had a case of Pneumocystis pneumonia. We usually see that in people who are on cancer chemotherapy, but this was a young gay man who is not on cancer chemotherapy." This was also in early 1981.

Alvin Friedman-Kien

Owen: So I heard these things. I called up Dr. Groundwater and I said, "Do you know this Dr. Friedman-Kien?" He said, "Oh, yes, I talk to him." I said, "Is there any way that you could ask him to come out for our meeting in June?" I think it was only a week or two before that, right around the time the first [Pneumocystis] cases were reported in MMWR, too. That was, I believe, in June of '81 also.¹ So all these things were coming together to a crescendo at one time.

Hughes: Was Dr. Groundwater a friend of Friedman-Kien?

Owen: I don't know if he knew him just as a professional colleague or what, but somehow he was able to get him to come out here.

Hughes: Friedman-Kien is gay, isn't he?

Owen: Yes.

Hughes: So could some of his motivation to speak at the BAPHR meeting have been, This is a strange disease happening to my community, so I should help it out by giving a presentation? Some physicians in New York would hesitate to fly out to a minor medical gathering. I don't mean to be disparaging, but most mainstream physicians wouldn't have heard of this group.

Owen: Right, and of course, Friedman-Kien is still very much with us. You might want to give him a call and ask him his motivation back then. I don't think we had enough money to pay anyone for a trip like that. My guess would be that he paid for the trip himself.

Hughes: Angie Lewis, who at the time was a nurse-educator at UCSF, attended that meeting. One of the comments she made in her oral history was that the slides were all hand-drawn, implying that Friedman-Kien hadn't been given much time to prepare his talk. Do you remember any of those details?.

Owen: No, I don't remember the details. I think he did show us pictures of the purple lesions. But maybe in discussing numbers of Kaposi's sarcoma (KS) cases that he had seen, that very well might have been hand-drawn, because it was short notice. We didn't have sophisticated computer methods where you could go to your PC (personal computer) and crank out a slide in a day. It was a much more involved process back then.

Hughes: What was your reaction?

Owen: Shock. I remember at that time just starting to think about the implications of this. It's very small numbers, but what does it mean down the line? Where are we headed with this? When am I going to see my first case in my practice?

Hughes: So you didn't think, this is an ephemeral phenomenon in New York that science is going to solve and that will be it?

Owen: No, because by that time, as I mentioned, there were these few odd cases reported from San Francisco as well, and the MMWR reported cases in New York and Los Angeles. I don't think they included San Francisco in that reporting. So it was clearly something that was happening in multiple places.

Lymphadenopathy in Gay Men, 1979 On

A Memorable Case

Owen: I guess I should back up to when I started practice, which was 1979. From the first week I went into practice, I started seeing cases that I couldn't explain, and for at least a couple of years

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1 See the oral history with Angie Lewis in the AIDS nurses series.

2 CDC. Kaposi's sarcoma and Pneumocystis pneumonia among homosexual men--New York City and California. MMWR 1981, 30:305-307 (July 3, 1981). The MMWR article does not list by city the eight KS cases California reported to date to the CDC.
until these Pneumocystis and KS cases were reported, these things remained mysteries.

Hughes: Such as?

Owen: The main thing was generalized lymphadenopathy, young men who were coming in with substantial lymph nodes all over the neck, armpits, and the groin. As an example, I remember my first week in practice, I had a patient, Dr. Jerry Babbitt, come in to my office who didn't remember me, but he had been my resident when I was doing pediatrics at St. Christopher's Hospital in Philadelphia. I was a medical student at the time. So I was in my junior year and he was already a resident.

I mentioned that my sister went to medical school, and in medical school she did a preceptorship in New York City, and he was the preceptor for her.

Hughes: How coincidental.

Owen: Isn't that amazing? So he walks into my office, and I practically drop dead to see this guy who had been my resident and I remember my sister telling me that she had worked with him. He said, "I've been really bothered. I've been having these nodes come up all over." So I went over him very carefully, and of course found the nodes, but couldn't find any other underlying things that would explain it.

So like a thorough internist, I performed a thorough physical examination. I did a battery of lab tests. I still couldn't come up with any answer. So the next logical thing would have been to take a biopsy, and so we referred him to a surgeon for a biopsy and analysis. The pathologist at St. Luke's looked it over, and couldn't come up with a diagnosis at all. It just looked like benign reactive hyperplasia, which means that the node was reacting to something, there were a lot of lymphocytes in it, but they couldn't tell what it was reacting to.

So I said, "Well, there must be something wrong with the pathology department here at St. Luke's. I'm going to send him off to the university." So I sent him off to UCSF, and he was examined there, and they found nodes. They said, "Well, you need a biopsy." So they did a biopsy and sent it off to their pathologists. Their pathologists came up with a diagnosis of benign reactive hyperplasia.

So this physician came back to me and said, "Well, what will I do now?" He still had the nodes, and he might even have been having some low-grade fevers too. I said, "Well, obviously that
university just doesn't know its thing, so we have to send you off to another university." [laughter] So we sent him to Stanford, and again he was very thoroughly examined and some lab tests done, and they said, "You need to have a lymph node biopsy." So they went ahead and did a lymph node biopsy. And again, guess what? It came back benign reactive hyperplasia.

So by this time, both he and I were thoroughly perplexed, and of course, there is that feeling of impotence when you find something wrong, but you don't know what is happening.

Hughes: Were you thinking about a possible link with homosexuality at this stage?

Owen: Yes, because just gay men were coming in with this generalized lymphadenopathy. So I had this collection of people that I could rattle off who had these lymph nodes that I didn't know what was going on, and from a number of them I had biopsies obtained too.

Hughes: How could you have been sure that physicians seeing heterosexual patients weren't running up against the same thing?

Owen: Well, at that time, my practice was probably 40 percent gay men, who were mostly coming in for benign sorts of things, minor sexually transmitted diseases, and the other 60 percent of my practice was standard internal medicine. But standard internal medicine is primarily elderly people, and their routine problems are maybe congestive heart failure, or diabetes, or high blood pressure. And among those patients, of course we didn't see any lymphadenopathy.

Hughes: So you did have a comparison.

Owen: Yes. That wasn't exactly an age-matched control group. If I had seen a lot of heterosexual men of the same age group, the question would have been, would I have seen lymph nodes in them? I had a few in that age group but not too many, and certainly in those few I didn't see that kind of presentation. Nor had I ever heard through all of my training of anything like that among men in general.

My feeling was that it was probably some type of a virus. At that time, we had reports of the first tests for CMV [cytomegalovirus]. Larry Drew, who was a virologist at Mt. Zion Hospital here, and is still very active in that research area, did a lot of the work over the years in CMV, so we thought, Well, maybe it's that. We did CMV titers on them, and they all turned up positive. So we thought, Well, maybe it is the causal agent;
perhaps we're just not seeing the virus in the biopsy specimens. But at that time, we just didn't really have an answer.

Centers for Disease Control

Owen: And then a couple of years later when these first cases were reported, the CDC sent out Harold Jaffe, who was still with the epidemiology branch of the CDC, to talk to gay physicians and to find out what were we seeing. Were there other cases that maybe hadn't been reported? Is this a bigger phenomenon? And in this meeting between Jaffe and gay doctors I said, "I have this whole large number of men who have these lymph node enlargements," and everyone in the group said, "We're seeing that too." So that's when I think the CDC became really aware of people with enlarged lymph nodes.

Then Donald Abrams got credit in the MMWR for reporting persistent generalized lymphadenopathy in homosexual men.¹

Hughes: Your name is listed as a case reporter, and his isn't, strangely enough.

Owen: Oh, it is?

Hughes: Donald told me that he was a bit annoyed that he wasn't credited.² Anyway, when did you first begin seeing the lymphadenopathy?

Owen: '79.

Hughes: '79, as soon as you started your practice.

Owen: October 1, '79, is when I started my practice, and I saw this physician, my former resident, I think some time that month. He was one of my first patients.

Hughes: Anything else between 1979 and December of 1981 that you now look back on and realize was an AIDS case?


² See the oral history with Donald I. Abrams in the AIDS physicians series.
Owen: I think there was a case of shingles. None of the major opportunistic infections, though. I didn't have any deaths that were unexplained. The only one was that case at UC that wasn't even directly my patient, way back in my training in maybe '77, '78. But then the reason for that, retrospectively, is just that the people were all so early in their disease. So unless somebody had a really rapid progression of disease at that time, you wouldn't see them in the later stages. They were all just getting infected. It was '78; about one percent of gay men in San Francisco were HIV-positive, as we know retrospectively because of the hepatitis B study data. But I think the peak years of initial infection were in '81, '82, '83. So as we were learning about the epidemic, people were still getting infected in a major way.

More on the June 1981 BAPHR Conference

First Presentation of "AIDS"

Hughes: Well, is there anything more to be said about BAPHR's annual conference? That was an early time for a medical gathering to be discussing this disease. Is that not true?

Owen: A lot of people in writing the history of AIDS don't give credit for that, but I think it was the first medical conference in the country at which what was later known as AIDS was presented.

Hughes: So that was June of 1981. In September of 1981, NIH had a conference, which is the one usually billed as the first medical conference on what became AIDS. But it obviously wasn't.

Owen: Oh, you'll have to correct that.

Hughes: Right. Well, in reference to the BAPHR conference, do you remember talking with your colleagues about Friedman-Kien's presentation?

Owen: Oh, yes, very definitely. My mother was receiving the MMWR and reading it, and she sent me the very first article to appear on Pneumocystis in gay men, and she said, "Have you read about this?" Of course, I had received my own copy too, so I said, "Yeah, Mom,

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I did." So it was really starting to alarm even a few lay people at that time.

Hughes: My heavens, that's amazing. Did you make any correlation at that stage between the PCP cases and the KS cases?

Owen: Well, yes. I hadn't actually seen directly any KS or PCP [cases] myself. So my linkage was more with these reported cases and these lymphadenopathy cases I had been seeing in my practice.

Defining AIDS

Etiology

Hughes: How did you define this series of conditions at this very earliest time?

Owen: Well, we knew at that point that it had something to do with immune compromise. Why people were immune compromised, we weren't really certain. We didn't know whether it had to do with some sort of an infection, or was it a lifestyle matter? Was it that people were being exposed to these things because they lowered their immune system through drug use? Poppers [inhaled nitrites] were speculated on. Was there some genetic condition among gay men that made them more susceptible to these infections? And of course, at that time, we just didn't really know. We were talking about all these different possibilities but were kind of at a loss to say what it was really caused by.

Hughes: You didn't have any particular hypothesis of your own?

Owen: No, I don't think so. I think that we were really open to all possibilities. That's why when physicians would get together in BAPHR, we would talk about our own experiences and what we had seen.

CDC's Role

Owen: Certainly in the meeting with Dr. Jaffe, the whole thing concerning possible etiologies came up. People just tried to brainstorm and think of different possibilities, and the CDC doctors wrote them all down. It was something that the CDC wanted
Hughes: Was the meeting with Dr. Jaffe a two-way exchange?

Owen: No, I think he mostly wanted to hear from us. He might share with us statistics from other cities, because of course the CDC had all the latest epidemiology, which we were really interested in. We were following the numbers month by month at that time.

Hughes: In the summer of 1981, what was initially called the CDC Kaposi's Sarcoma and Opportunistic Infections Task Force had been formed.

Owen: I remember that Mary Guinan came out too.

Hughes: And what did she do?

Owen: She was a physician researcher. She also did things similar to Jaffe. She talked to us, I think it was in groups, about our feelings about anything that might be related to this epidemic that we could pinpoint, that we could explain, and were there any other cases that maybe hadn't been reported that we could think of? I think it was primarily a fact-finding mission.

Hughes: And this is what the CDC was doing in various cities?

Owen: Right.

Hughes: Do you remember hearing anything about the CDC case-control study?

Owen: Oh, what did they come up with?

Hughes: They reported that the greatest risk factor for what was now being called AIDS was number of sex partners.¹

Owen: Right. I wonder if they got any data from my patients on that.² After the lymphadenopathy meeting, Jaffe and Guinan went back to the CDC and decided they would ask us to submit specimens from the patients so that they could study them for any kind of information. So I entered several of my patients with

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² William Owen is listed in the acknowledgments.
lymphadenopathy on that study. I think they also wanted lymph node tissue if possible, and they also wanted lots of blood, so the patients had to come every month or so to give blood. That was one of the earliest studies that CDC did on the epidemic.

A "Gay" Disease

Hughes: Did Jaffe and Guinan talk about the case definition in these discussions?

Owen: No, I think it was even before it was called GRID [Gay-Related Immune Deficiency]. It was still KS/OI [Opportunistic Infections]. And then for a while, it was GRID, and then AIDS later on.

Hughes: Did you use the term GRID?

Owen: I didn't particularly care for it, because I had the feeling that the epidemic perhaps went beyond gay men. Then that was shortly verified, because some of the first reports then came out on hemophiliacs and blood transfusion recipients with AIDS.

Hughes: The label of a "gay" disease didn't particularly bother you?

Owen: Well, at that time, just about 100 percent of the patients were gay, so I can see why that was done at that point. Retrospectively, of course, it was wrong, and politically it probably wasn't the best thing either. Even though lesbians were at much lower risk, the stigma carried over to gay people in general.

Hughes: On the other hand, the initial construction as a gay disease was a rallying point. It served to mobilize people.

Owen: Yes. And it probably led also to the development of the very early community organizations that were helping people with AIDS along, so the community was able to come together around this issue.

Hughes: In your practice, was lymphadenopathy the most obvious aspect of the disease?

Owen: Yes, at that point it certainly was.
Seroconversions

Owen: The other thing that was happening, and of course, I didn't have a handle on this at this time either, was that there were people who were coming in with a mononucleosis-like illness, where they had severe fatigue, fevers, perhaps sore throat, swollen glands, perhaps a little rash. And it went on for much longer than mono, maybe for a few weeks in many cases, and then the symptoms went away. Some of these cases we thought perhaps were scarlet fever because of the rash, and sometimes maybe streptococcus was isolated from the throat. Other times we thought maybe it was an acute CMV illness.

Retrospectively, it turns out that a lot of these men were having their first seroconversion that was being represented by these symptoms. And years later, I could tell that, because people would come in to my office and they would say, "Bill, look back in your record for July of 1981," or "December of '90, and see what you can find there." And sure enough, there was a description of this whole thing that later became known as the primary HIV syndrome, where people were seroconverting and developing these mono-like symptoms. So we were also seeing that and weren't aware of what that represented.

AIDS-Related Complex [ARC]

Hughes: Was ARC a category that you used at one stage?

Owen: Oh, yes, we used that for a number of years.

Hughes: What did that mean to you?

Owen: Well, it was a stage between asymptomatic or lymphadenopathy and full-blown AIDS. These were patients who were developing signs of immunosuppression, such as oral candidiasis, thrush, hairy leukoplakia, shingles, diarrhea, fevers, weight loss, but weren't developing any of the full-blown AIDS diagnoses. So it was really another name for what we today would call symptomatic HIV disease.

Hughes: Did you think of it as a prodrome to full-blown AIDS?

Owen: Yes.

Hughes: Rather than something else that might or might not be AIDS?
The term means AIDS-related complex. So the implication was that it eventually led to AIDS.

Donald Abrams initially called it pre-AIDS. He hoped that these people were indeed mounting an effective antibody response and would not progress to AIDS, which of course turned out not to be true.¹

Right.

But you didn't have that perception?

As far as the lymphadenopathy goes, we really didn't know where that would lead. We didn't know whether it would maintain itself as some sort of benign thing, or whether it would go on to develop these other conditions. Our worst fear was that it would go on to develop these other conditions. But at that time, it was too early in the epidemic to know. Even today, the average time to development to full-blown AIDS is ten, eleven years. So we had no way of knowing whether that lymphadenopathy would in fact progress to AIDS, but that was our fear.

The CDC Definition

When the first CDC case definition of AIDS was created in 1982, did you indeed use that in your diagnoses?

Oh, yes, we did use it. At that time, we still didn't really have that many patients that met the diagnosis, the case definition. They were still having all these other kinds of symptoms that didn't quite fit.

Because the AIDS-defining conditions were still being assembled?

Yes. And were still uncommon, because of the lag time. Only 1 percent were infected in 1978, so if you're talking about 1983, for instance, that person would have only been infected for five years. So only a certain percentage of people would have been likely to develop full-blown AIDS at that point. You wouldn't expect most of those infected in 1978 to have developed AIDS until 1988.

¹ See the oral history with Donald I. Abrams, M.D. in the AIDS physicians series.
And only one percent of gay men in San Francisco were infected in 1978, so most were infected later and wouldn't have developed AIDS until the 1990s. Which in fact is when the peak occurred in the diagnoses, and since then it's been actually going down.

Hughes: Were there conditions that you considered to be AIDS-defining that were not yet in the official CDC definition of AIDS?

Owen: Oh, yes. For instance, this young physician that I told you about, Jerry Babbitt, had been going on with his lymph nodes for years and was feeling fairly healthy. And then around 1983 or maybe '84, he started to develop very high fevers. So we went over him again, found his nodes, but at least one of the nodes felt very different this time. It was much larger, much harder. So this time we sent him off for another biopsy, and it came back as non-Hodgkin's lymphoma.

Well, my feeling was at that time, This has got to be related to the newly coined term AIDS. But at that time, it wasn't part of the case definition. We treated him with chemotherapy; he didn't respond very well to it. He was in horrible distress. He made a suicide attempt which was unsuccessful. Somebody actually rescued him, which he didn't want to be. And shortly thereafter he ended up dying anyway. That was a real tragedy, because of what he went through. Plus I think I personalized it even more than maybe other people, because he had been my resident as a medical student. It's like I lost him. He died without even having diagnosis of AIDS. I don't know if it made much of a difference in terms of the treatment or anything--well, that's what we dealt with at the time.

Hughes: There really wasn't much that you could do in terms of treatment?

Owen: Yes, really, there wasn't. At that time, I don't think we were very good at treating even the opportunistic infections.

A Patient with *Pneumocystis Pneumonia*

Owen: My first patient with *Pneumocystis* pneumonia came in in early 1982. I ended up a few years later treating his brother; his only brother had AIDS also. Anyway, this guy moved here from southern California. He was going to be the fundraiser for Grace Cathedral. This was early '82.
But for the preceding months before he moved up here, he went from doctor to doctor. He lived in Orange County. Just all kinds of specialists--infectious disease physicians, hematologists, rheumatologists. Nobody could figure out what was going on. By then these specialists would have heard, even through the news, about AIDS, but nobody did the tests. He was complaining of shortness of breath.

He got up to me the day before he was supposed to start this new job at Grace Cathedral, and his skin color was blue. So we got the x-ray, and it was very abnormal, and the measure of his oxygen level, which is called a blood gas, was very low.

I thought, Well, we have never seen a case of Pneumocystis at St. Luke's. Even though I'd like to take care of him, I think probably he'll get the best care at UCSF. So I called Donald Abrams and I asked if he would be willing to take him, and he said sure. I think he was doing his fellowship in oncology. So we sent him over there, and his oxygenation was so poor they had to put him on a ventilator. They gave him pentamidine, which was only available at that time from the Centers for Disease Control via overnight mail. But he was so far along at that point, he didn't respond; didn't make it.

The problem was that a lot of patients were coming in late, and a lot of doctors were perhaps making the diagnoses too late. We just weren't as sophisticated about the disease as we are today.

Hughes: But you recognized immediately that he had Pneumocystis?

Owen: Oh, immediately, yes. Once he reached me, there was no delay. Even though I had never before seen a case of this, I throughout the preceding months had been reading with horror about so many of these cases, every month seeing these numbers increase. I read everything I could find about Pneumocystis at the time, which mostly was in oncology patients who were immunosuppressed. I had read enough about it that I was prepared when I saw my first case and was able to recognize it. But he came in so late.

**Kaposi's Sarcoma in San Francisco**

Hughes: How much KS [Kaposi's sarcoma] were you seeing?

Owen: Not very much. My first case might not have been until about '83. It was this guy by the name of Bobby. He was a friend of another
friend of mine, who was a physician who since has died of AIDS too.

Hughes: Now, is that somewhat because you are in internal medicine, and if somebody spotted a strange lesion, they'd be more likely to go to a dermatologist or an oncologist?

Owen: Well, it's possible, but I think also the numbers of KS cases in San Francisco probably were still relatively low at that time.

Hughes: Compared to PCP?

Owen: Yes. You could go back and see what the numbers were, I suppose, I have that because I get the printouts from the San Francisco Department of Public Health, and I think they have annual data on that too. [tape interruption]

The Kaposi's Sarcoma Clinic, UCSF

Hughes: Did you have any links with the KS Clinic at UCSF, either in terms of sending patients or going to the meeting that followed the clinic?

Owen: No, I didn't have any connection with them.

Hughes: Did the BAPHR group know that the clinic existed?

Owen: Oh, sure. And I'm sure I referred patients over there, but I wasn't actually working there.

Hughes: Did any of the BAPHR physicians work there?

Owen: Yes. One person that you should probably have on your list of people to interview is Dr. Bolan.

Hughes: Yes, I do have him on my list.¹

Owen: He's in southern California now. He heads up the AIDS unit for family practitioners at the University of Southern California Medical Center. So he went from private practice into academic life. In fact, I just talked to him this week. There's this HIV symposium that we have every year now that attracts the top AIDS specialists from throughout the country, and we alternate between

¹ See the oral history in this series with Robert K. Bolan, M.D.
Laguna Niguel, California and Arizona. This year we're having it in Scottsdale. They have a whole day devoted to managed care--that's how things have changed. One of the sessions is on use of the computerized medical record in care of HIV patients. So we're going to be on a panel together discussing that.

**AIDS Prevention**

Hughes: What were the links, if any, between you practitioners in the trenches, so to speak, and academic physicians.

Owen: I think the big link was in prevention. As part of BAPHR, we had a committee called the Scientific Affairs Committee, which met quite frequently at that time. This committee actually devised the first safe sex guidelines that were published. On that committee, there were people who were at the university. Do you know Harvey Bartnof? He coordinates the big AIDS course that UCSF gives every year. Harvey used to come to that committee meeting. Bob Bolan was also very active. Dr. Jim Campbell was the head of that committee. He's been in practice in San Francisco for many years, had a large gay practice for years. Jim would be a good one to give you the history of BAPHR's Scientific Affairs Committee and the safe sex guidelines, and how they came about and were the first to be published.¹

**Stance on Recommending the HIV Antibody Test**

[Interview 2: April 23, 1996] ##

**Initial Opposition**

Hughes: Dr. Owen, I want to start this session by asking you to describe the procedure that you go through with a patient who you suspect or know is HIV positive.

Owen: Well, I think there would be a difference in terms of the approach to somebody that I suspect of having HIV versus those that I know have HIV. For the ones where there is a suspicion, of course, that implies that the test has not been done, so that would be

¹ See the oral history in this series with James Campbell, M.D.
part of an exam where the topic came up, or even part of a routine physical exam where I asked about HIV status. I would discuss the importance of doing the test, along with a discussion of its limitations, the fact that the standard test, the ELISA test, takes a while before antibodies are developed. So if in fact the individual had exposure within a certain period of time, it's possible the test might not come up positive even if the individual had seroconverted.

When the test first became available in the summer of 1985--it was available to blood banks before that, but it became available as far as a test that could be ordered at, let's say, an anonymous test site--I counseled against it at that point. The reason for that was that there was really nothing that we could do about treating positive HIV status.

So it would cause lots of worry and anxiety and depression about something that we couldn't really doing anything about. The other argument went that, Well, suppose you could use test results to counsel about safe sex. Well, the retort to that was, Well, we already are counseling about safe sex, and we advise that everybody should practice safe sex. So there wasn't really any medical reason that I could think of to recommend that test.

Favoring the Test

Owen: Now, in late 1986, something happened, and that something was AZT. So for the first time, we had available to us an agent that at least at that time promised to do something in terms of slowing down progression of disease. So I changed my opinion about testing 180 degrees at that point. If you look at my medical records, you will start to see the appearance of helper T cells counts, which I had never ordered before because there was nothing I could do about those, and also an HIV test result I didn't keep as part of the record. I had people do those at an anonymous test site, because that was really the only way we could figure out at that time to keep it off the record.

The fall of 1986 marks a watershed in terms of my change in direction. I think I was one of the first physicians around to actually recommend taking the test. For a couple of years thereafter, I know a lot of physicians were still advising their patients not to get tested, and a lot of gay community organizations were very much against testing at that point.

Hughes: Including BAPHR at one point.
Owen: I'm not sure when the point was that they changed, but I think they lagged behind my clinical practice in terms of their recommendations.

The first community organization, as I recall, to recommend the test was Project Inform, and I think that was some time in mid- to late '87, about a year after I started recommending it. Well, that was really a major turning point for the community. I had gotten a lot of resistance to patients doing that. After a group of people, Project Inform, who were perceived as perhaps not being in the medical power structure, recommended that it be done also, then we started to see a major change. A lot of people seemed to be willing to come forward and do it. So we have this small number of T cells counts appearing in the medical charts for people who are positive and checking their immune status in '86, and then we have this much larger wave starting in late '87.

Confidentiality

Hughes: Do you still keep the results confidential?

Owen: Oh, it's up to the patient. In probably the last three or four years, we had requests from a number of patients to do the test through the laboratory here at Davies Medical Center, but the patients also wanted to keep it off the record. The idea there was that even though they had to pay for the test, the turnaround was much quicker. We could do it one day, and we could get a result back in three days or so. Whereas at the anonymous test sites, it's still taking about two to three weeks to get an appointment, and then taking another two weeks to get the results back.

That waiting time can be very difficult for patients. It's a time when people are constantly mulling over, Am I positive? Am I negative? What am I going to do if this happens or that happens? So it's a very anxiety-provoking period. So to shorten that to just a few days is a benefit in the minds of many patients.

We have a consent form, but we kept the order form and the consent form and the result when it arrives off the record. If the patient wishes to do it under a pseudonym, that's totally fine, but if they want to keep it under their name, that's also fine, but it just does not become part of the record, whether it's positive or negative. So that's the way we've been handling it now, and that seems to have worked out very well.
Hughes: How were you using the T-cell levels in those very early days? Because if I remember correctly, it wasn't apparent that prescribing AZT from the outset was a good idea.

Owen: No, it wasn't. After the first studies were done, in fact, you could only get AZT for people who either had full-blown AIDS as defined by an opportunistic infection, such as *Pneumocystis* pneumonia, or AIDS-related complex or ARC, as they called it then, with a helper T-cell count below 200. Of course, now the definition has been changed and CD4's less than 200 are defined as AIDS. But back then, it was called ARC, and you needed those criteria in order to get AZT. So as a result, we started to order T-cells so that we could define where people stood in terms of their immune status.

Hughes: So it was either you qualify for AZT or you don't. What about dosage?

Owen: The dosage then was set at about twice what we're prescribing today. It was a very, very high dose. It's what led to a lot of people having stories about toxicity of the drug, and why many friends of people who had taken these large doses were unwilling to take AZT. So that was its own problem.

Opportunistic Infections

Owen: But the other reason that we recommended testing and doing helper T cells was that at that time it appeared that we could actually make a difference in terms of preventing some of the opportunistic infections that are associated with AIDS.

Aerosolized Pentamidine

Owen: The Community Consortium did one of the first studies in the country to show the benefit of prophylaxis. The idea for this actually came from members of the community, because they had heard about people in other cities experimenting with an aerosol version of pentamidine, which is traditionally an intravenous drug used to treat *Pneumocystis* pneumonia. Patients even outside a
formal medical practice were doing these inhalation treatments with pentamidine.

Hughes: Had the treatments been devised for a traditional medical setting?

Owen: Who actually was the first one to devise this, I'm not even sure. It might have even come directly from the community, like a guerrilla medicine kind of thing. But when patients here got wind of it, they wanted to try to use it too. We said, "Well, wait a minute. We don't even know if this stuff works or not. Let's set up a study and see what happens." We tried different doses of aerosolized pentamidine in comparison with--I believe it was a placebo, or maybe it was not doing anything at all. No, I think it was three different doses. I think everyone got the pentamidine.

It turned out that it did seem to have benefit, especially in a particular dose, 300 milligrams once a month. So we went ahead, and the FDA ended up licensing that treatment shortly thereafter.

Since then, we realized that trimethoprim sulfa, Bactrim or Septra, actually may be more effective and certainly is less expensive than aerosol pentamidine. But it was interesting that very early on, in the '86-'87 time frame, we already were starting to do prophylaxis for opportunistic infections. So it was another reason to consider doing counts of CD4 cells, because if the patients had below 200 CD4 cells, they were considered to be at high risk for Pneumocystis pneumonia. Whereas above 200, they were not.

So aerosolized pentamidine prophylaxis was something that encouraged me to advise patients to get tested, and then if they tested positive to see where their immune status was right then. We felt, and still feel, that we could prevent some of these deadly infections associated with HIV disease by early knowledge.

Tests Measuring HIV Activity

Hughes: Have we said enough about what you do when an HIV-positive patient presents himself or herself?

Owen: Well, we talked about the group that was not aware of their HIV status. We worked into what we do with the group that turns out to be positive: we did helper T cells at that time.
Some time after that, we were looking for a measure of the activity of the virus, and we started to do a test called p24 antigen, which showed levels of activity in some patients, but it certainly wasn't consistent, and it didn't always reflect treatment changes either. We did those and another test for many years because we had nothing else. The other test, called the beta-2 microglobulin, was supposed to measure the general level of inflammation in a person. Both of those tests have been abandoned completely, because in late 1994, shortly following the Tenth International AIDS Conference in Yokohama, we realized the usefulness of viral load measurements. So now we're doing those, using either the bDNA [branched DNA] test or the PCR [polymerase chain reaction] quantitative test.

Hughes: Are both those tests available at Davies?

Owen: Branched DNA is the one that Davies has centered on. It's one that a small hospital can do relatively easily in its own clinical laboratory. So in the fall of '94, I instigated the hospital to start that, because I realized that they were using this test in a number of research studies and it looked very promising in terms of measuring the effect of various therapies. I thought it also would be helpful for a variety of reasons for indicating when to initiate therapy, when to change therapies, when to stop therapies. Of course, in the mid-eighties when we started to do CD4 testing, we didn't have a test for viral loads.

Hughes: So viral load became the key indicator, tied in with branched DNA technology, right?

Owen: Right.

Hughes: PCR is more complicated to do?

Owen: PCR is more complicated for labs to do, but a number of the commercial labs have set up the Roche test, another quantitative test. They basically use two different technologies to achieve rather similar results. Considering how different the approach is, the results they get are not directly comparable, but at least they seem to follow the same trends. When the viral load is going up in one, it's going up in the other test, and when it starts to show response to a medication, and viral load starts coming down, we see it coming down in the other test. So the lines parallel each other.

Hughes: Does this mean that you can now fine-tune dosage?

Owen: Yes, you can fine-tune the treatments.
David Ho's Work on HIV Replication

Owen: And the other thing we've learned in the last year through David Ho's work in New York at the Aaron Diamond Research Center in New York City and through the work of the virology group at the University of Alabama, Birmingham, is that the virus replicates extremely rapidly. See, for many years, we thought that the virus was very slowly picking off T cells in the immune system. We thought the T cells were static too: you were born with a certain amount of them, and in HIV disease you're gradually losing them.

Well, the revelation here came in January 1995 with the publication of Dr. Ho's data, and it showed that the virus in fact is replicating extremely rapidly and is also destroying helper T cells at a very rapid rate. The interesting thing was too that it turns out that the CD4 cells are turning over. New ones are developing even as they're being destroyed.

So it's a question of this battle of the titans, very tiny titans, and whoever wins that balance can be measured by the viral load too. If the viral load is very high, you know that the virus is winning that battle and the CD4's are getting destroyed. If the viral load is very low, then you shouldn't have as many CD4 cells being lost.

Hughes: That theory also explains the long incubation period, because the immune system is keeping the virus in hand, right?

Owen: Right. The immune system—in most patients, not all—does a really remarkable job for many years.

AIDS Medicine: Multiple Dimensions

Immunology

Hughes: Has this disease forced you to learn more about immunology than you had needed to know before?

Owen: Oh, yes. I think we learned in the seventies about B cells and T cells, but I don't think we learned anything then about helper T cells or suppressor T cells and their function, later called CD4 and CD8 cells. So yes indeed, we've learned an incredible amount. But I think a lot of that knowledge about immunology has developed because of this epidemic.
Hughes: There are several components of your treatment protocol. I'm thinking of the nutritional advice that you give and the psychiatric component. Is this atypical of how you were used to practicing medicine?

Owen: Of all specialties, in internal medicine, you always took a very thorough history, and you always did a thorough physical examination. So I think those things have carried me very well into this epidemic, because you have to be very thorough about your patient history, and you have to also be very thorough about your examination. Sir William Osler, I think, used to have a saying about syphilis: Know syphilis, and you will know all of medicine. And I think syphilis has been replaced to a large extent by HIV disease. You really have to have a very broad knowledge about all the organ systems of the body, which is what internal medicine provides.

**Nutrition**

Owen: But beyond that, there have been other things that we employ that weren't emphasized when I was in medical school and in training. As you mentioned, knowledge of nutrition. We have to really be aware of the patient's nutritional status, be able to monitor that in an ongoing basis. We have to be able to intervene appropriately when it appears that that's not going in the right direction.

Hughes: I suspect that nutrition was not particularly emphasized in your medical education.

Owen: No, not at all. I think we spent an hour or two on nutrition on a Saturday morning. It wasn't very easy going to lectures for eight or nine hours on a weekday to get people to come to lectures on Saturday morning. And they were very basic, very elementary, and they really weren't the comprehensive lectures that we should have had. So yes, there was a great learning curve there.

**Safe Sex Counseling**

Hughes: Did you consider safe sex counseling to be part of your responsibility as well?
Owen: Sexual questions weren't really emphasized in medical school and in training.

Hughes: I mean in your medical practice.

Owen: Oh, of course, it's changed. But it changed even before the AIDS epidemic, because when I worked in the emergency room at UCSF, I encountered a lot of sexually transmitted diseases that I had only read about in books, and I realized that it would be very important to take a thorough sexual history to determine when individuals were being put at risk for different diseases. So I started employing a sexual history fairly early on in the San Francisco part of my career, even before HIV was known.

Being "Out" as a Gay Physician

Hughes: Did you find it expedient to make it known somehow that you were a gay physician, and hence gay patients could be frank about their sexual history?

Owen: Well, you know, in the emergency room at UC, I certainly didn't announce it, but some of the clerks and people who got patients checked in to the emergency room happened to be gay, and they knew of my interest in that area. I suspect that probably in many cases, they clued patients in: "This is a gay physician."

But then when I started my practice, I was very "out". As a physician, I put my ads into the gay papers that I had started my practice. A lot of my patients were referred by friends who obviously knew that I was gay and these patients wanted to have a gay physician. I listed my name in all the gay directories. So for the whole practice part of my career, I've been very open, and I think that that's been important for a lot of people. It still is.

I have a new patient who just came to me last week who is very, very closeted. He's thirty-nine, just starting to come out at a fairly late age. He works in the defense industry in Silicon Valley. He felt that he could just not bring this up with his physician down there. He's afraid of somehow the government finding out, with the defense connection. So he is very comfortable in knowing that there's somebody here that he can discuss things with in an open manner and not be afraid to bring up his lifestyle.

Hughes: So being "out" really is integral to your medical practice?
Hughes: Some maintain that the early emphasis in AIDS drug development was on antivirals rather than treatments for opportunistic infections. You in clinical practice might have been aware of that emphasis.

Owen: I think we were really focused on everything. We knew that if the virus was the thing that knocked off our patients' immune status, particularly in the case of people at higher levels of CD4 cells, we needed something to prevent their CD4's from falling lower so that we could hopefully avoid those opportunistic infections. At the same time, for our patients who were at risk for opportunistic infections, we realized that we didn't have effective prophylaxes or treatments. So we knew that HIV disease needed to be fought on a multifront battle.

Hughes: Did you feel that it indeed was?

Owen: Well, I think so. I'm thinking about CMV treatment, for instance. Ganciclovir really started to come about in the mid-eighties, just about the same time as the first antiretroviral drug, AZT. And, as I mentioned, the Pneumocystis prophylaxis studies were being done at that time. Drugs for Mycobacterium avium infection took longer to develop. I wish we had had them earlier; we would have probably saved a number of lives.

Hughes: Was their slow development because of lack of emphasis, or was it just the natural progression of drug development?

Owen: Yes, some of it was related to the historically long lead time of drug development in this country, but those drugs I believe were available, at least experimentally, in Europe. The FDA moved very, very slowly on those approvals. Today, if in Europe they developed something that looked promising, I think those drugs would be in clinical studies much earlier in this country. But at that time, things just moved so slowly. They were used to the traditional method of drug development, which took place over decades, rather than years, let alone months. But I think there was some bureaucratic inertia that was present there as well.
Hughes: Is there any explanation for the flow and flux of opportunistic infections?

Owen: Well, the most common in the early epidemic were the ones that a lot of researchers looked into in those years, and that drugs are available for, for either treatment or prevention. So we've been able to effectively prevent many of those infections in our patient population. Now, we're left with patients living longer and then being exposed to other infectious agents, as their CD4 counts get lower, that they wouldn't have been exposed to previously. So that accounts for some of it.

The other thing is neoplasms—cancers. We don't have a good prophylaxis for them, so we're seeing more malignant neoplasms in patients as their disease progresses. Patients are coming down with certain types of cancers, such as non-Hodgkin's lymphomas.

Hughes: Yet Kaposi's sarcoma is waning, right?

Owen: Waning as an initial diagnosis, but we're seeing it more as a late-stage diagnosis, where it's much more aggressive. It's more likely to go internal, producing Kaposi's sarcoma of the lungs, intestines with bleeding, a variety of complications. We're also seeing people, as they're surviving longer, now getting certain neurologic complications, too, where they're developing PML, progressive multifocal leukoencephalopathy, which is also a viral infection, which leads to a degenerative condition of the brain. So as we gain access to more effective prophylaxes and treatments, we're starting to see a variety of other, newer conditions appear that we hadn't seen before.

Hughes: This leads to the sad situation of greater longevity not necessarily leading to higher quality of life?

Owen: Right. Our goal is obviously to produce both longevity and better quality. To some extent, that may depend on at what point we intervene with effective drugs to prevent the immune system from falling down further. If we intervene when a person's helper T-cell count is 20, and it doesn't go higher at all, then that person might be very susceptible to a lot of these various infections that come along, and perhaps quality won't be possible.

On the other hand, I've seen patients who have had CD4 counts of 0 for four years and have very good quality of life. So there's no way that you can tell people that they can't try these

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1 The following discussion was moved for better continuity from its original position later in the transcript.
agents, because they do work in some situations. As an example, with the recent trials of the protease inhibitors, one drug, the Abbott drug ritonovir, was added to the preexisting regimens of all the patients who were in the study, all of whom had a CD4 count of less than 100. And what they found was a 50 percent decrease in death rate in patients who received ritonovir.

Now, this was very interesting, because a lot of drug companies have given up on testing these drugs in a very ill patient population, because of the thought that, Well, they're going to progress to death anyway at that very low level of T-cells, so why bother to study antiretroviral treatments in the sickest of patients?

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Owen: What other companies fail to realize is that something could be learned from these patients, because they are much closer to disease progression than patients who have higher levels of CD4 cells.

Abbott had the foresight to recognize that, and because of that, was actually able to see in a fairly rapid fashion--I think it was only six months--this dramatic decrease in death rate in patients who received their drug ritonovir.

Hughes: Some people hold that trials of AZT were curtailed, and that if they had been allowed to continue, some of the less desirable effects of AZT might have become apparent. Are we in danger of repeating that history with these new drugs because of the short testing period?

Owen: My feeling is no, simply because at that time, we didn't really have any markers to see what was happening to patients with these drugs. Today, we actually do. We have the viral loads, and it appears that the viral loads correlate with clinical progression. We know that patients who have less than 10,000 viral particles have a greater than ten-year progression to full-blown opportunistic infections. We know that patients who have over 30,000 viral load have a less than 4.5-year progression to opportunistic infections. So with this knowledge, we can look at viral loads and see what is happening with the patient, as well as looking at them clinically. In the mid-eighties, you really only had clinical progression to go by.

Hughes: So we're really playing a different ball game.

Owen: Oh, yes.
In 1983, BAPHR started an AIDS survey in which physicians contributed their experience of their patients with AIDS. Do you remember participating in that?

I probably did. I don't remember it specifically. You mean a questionnaire-type survey?

I've seen a case report form.¹

Jim Campbell started working around that time. He worked on BAPHR's safe sex guidelines, but another thing that he worked on was development of guidelines for diagnosis and treatment of HIV-related conditions.² In fact, today we talk about clinical pathways and guidelines with regard to managed care, but I think that BAPHR really had some of the first guidelines out there. They distributed them to members of our organization, but I believe it was also to members of the San Francisco Medical Society.

Has the epidemic changed your relationship with patients? Do you handle things differently now?

Yes, I think that I am a much more holistic physician, not in the sense of a physician who is into vitamins and herbs, but I think truly in the meaning of holistic, meaning looking at the whole patient, rather than just at the medical side of things. As we discuss the nutritional end of things, I think that exercise is also extremely important. There are some small studies that suggest that putting on muscle mass seems to be associated with better survival too, so we encourage patients to exercise through weight training or resistance training.


² See the oral history in this series with James Campbell, M.D.
Owen: We check testosterone levels to determine if there are deficiencies, and replace them if those are present. We look at the life situation of patients: what sort of supports do they have? Do they have lovers present? Do they have close friends? Is the family still a part of the support system? We look at issues related to death and dying. Do they have an individual designated for durable power of attorney for health care? Who is that person? We try to get a copy of it for the chart. So the epidemic has helped us actually view patients in a larger perspective.

Patient activism has also helped in that regard, too. Because patients have been very interested in seeing treatments developed, especially in the San Francisco Bay Area with groups like Project Inform and ACT UP Golden Gate, we have patients who come into our offices with reams of information or questions that they've copied from peers and that we need to be able to deal with and give them answers.

Hughes: Do you like that? Does that ever feel threatening?

Owen: You know, I really enjoy it. It's a challenge to have patients come in and to be able to discuss things with them. No, I don't see it as a threat at all. I'm sure there are some physicians who don't have a lot of HIV in their practices who may feel uncomfortable dealing with it; they feel threatened by that. But I really keep up with the literature; I keep up with my conferences. So if there is available knowledge, I certainly should be able to provide it.

Keeping Informed about AIDS

Medical Journals

Hughes: How do you keep up with the AIDS literature, which is so vast?

Owen: Well, there are several ways. I subscribe, first of all, to a number of journals. The most important ones, I guess, would be the New England Journal of Medicine, the Annals of Internal Medicine, Journal of the American Medical Association, the Archives of Internal Medicine. Also we get a number of HIV newsletters which give synopses of recent studies or that focus on patient care issues.
The other resource I have are more obscure journals. I asked the librarian at our medical center at Davies to produce a regular—and she does this every week or so—synopsis of the latest articles on HIV that have appeared on the Medline service of the National Library of Medicine, particularly focusing on HIV and treatment. So I get a computerized printout of that. If there are any articles that appear relevant, I can ask her to request the copy from interlibrary loan if we don't have the journal.

Medical Conferences

Hughes: How did you learn about branched DNA as a way to measure viral load?

Owen: I think that the biggest contributor to my knowledge about HIV and the way that I picked up on branched DNA was through conferences. That information was actually picked up at the Tenth International AIDS Conference in Yokohama. I attended the Third National Conference on Retroviruses and Opportunistic Infections in Washington, D.C., in January, and there was a lot of information on the use of a combination of protease inhibitors with reverse transcriptase inhibitors, triple combination therapy.

So conferences at this point are probably the biggest contributor to my knowledge, but journals are certainly an important adjunct, especially for certain obscure kinds of issues that might not be presented at a conference, or that are relegated lower down that you might miss.

San Francisco County Community Consortium

Hughes: Do you include the Community Consortium in the conferences that you find useful for recent information?

Owen: Yes. The way the consortium is set up is that in the first half hour or so we review a number of the studies that the consortium is doing. There's a social policy committee that reviews issues regarding AIDS, particularly that occur in the California state legislature or at the San Francisco Board of Supervisors level.

After that, we have a didactic presentation that rotates among all the major hospitals in the Bay Area that do a lot of HIV
care, and every hospital takes its turn to do one. And that's a very good source of new information, interesting cases that are presented.

In addition, the consortium sponsors conferences on various issues, generally held on Saturday mornings over here at Davies maybe two or three times a year. They had one recently on new antiretroviral treatments. They had one on Kaposi's sarcoma. They had one on CMV (cytomegalovirus) disease.

Hughes: So treatment-oriented?

Owen: Very, yes. And they usually have speakers who are researchers in the area. So those have been very good.

More on Medical Conferences

Owen: The International AIDS Society, which sponsors the international conferences, has also started to sponsor regional conferences in the United States through its IAS-USA organization. Last Saturday, for instance, there was one at the Sheraton Palace Hotel in San Francisco on new treatments in HIV disease and that went all day. It was an excellent conference. Tomorrow night, there's one downtown at one of the hotels that I'll be going to.

The other thing is conferences that are not presenting new information but that are a compilation of information. I have to pay tuition to attend. There is an annual one in Ft. Lauderdale, last held about a month ago. I'm going to a four-day conference, Clinical Options in HIV Care, in Scottsdale, Arizona--this is about the fifth or sixth one that I've attended. It's held every year and alternates among Scottsdale, Phoenix, and Laguna Niguel. They have researchers who are good speakers and bring the latest information there, and there's usually a lot of opportunity for discussion with the faculty.

Hughes: Do you feel it's necessary to keep up with the science, as well as the clinical applications?

Owen: Oh, yes. Usually basic science is part of these conferences. At this one that we had last Saturday at the Sheraton Palace, Jay Levy, who is the noted AIDS researcher at UCSF, presented a lot of basic information about the immune response to the virus, how the CD8 cells, the suppressor cells, act, and about other factors that he feels are instrumental in holding the virus in check. So that's very useful, and it's important to have knowledge about the
basic science so that when developments come along that use it, we can understand how they work.

Drug Trials

Hughes: Before the County Community Consortium existed, how did you learn about drug trials?

Owen: Well, there weren't any drug trials before that. The Community Consortium was started in 1985, I think, because we had our tenth anniversary last year, I believe. Dianne Feinstein, then the Mayor of San Francisco, inspired the creation of it. The only AIDS drug that was studied in 1985 was suramin, and that was at San Francisco General Hospital. Suramin was a horrible, devastating drug that was an anticarcinogenic drug used in Africa for African trypanosomiasis, I believe. It seemed to have some anti-HIV activity in the test tube, but patients who received it suddenly had an accelerated course of illness, and people who were clinically relatively healthy progressed within weeks and died. San Francisco General had a small center for that clinical trial, and I think I referred a patient to the suramin study. But there weren't many studies then.

There was something else then too. It was use of alpha interferon in Kaposi's sarcoma, and SFGH had an IL-2 [interleukin-2] study, probably '84-'85. So there were some studies around. I had forgotten about those. They were all based at San Francisco General.

So how did we find out about them before the consortium? It might have been through BAPHR, because the scientific affairs committee of BAPHR met on a fairly regular basis. In addition, as we mentioned in our last interview, BAPHR had annual meetings. At one of those meetings, Alvin Friedman-Kien revealed the Kaposi's sarcoma cases that he had encountered in New York City. But subsequent to that, there were also annual BAPHR meetings, too. So there might have been some information on AIDS at those.

The suramin study might have even been community-based; San Francisco General put an article about the trial into the Bay Area Reporter or The Sentinel, and patients just came. Since there was nothing else to treat AIDS, they could probably fill a study within minutes of announcing it, because people were going to jump on board.
Hughes: And there were a lot of AIDS patients funneling through the clinic at San Francisco General, too.

Owen: Right, SFGH enrolled patients in the study from their own patient population, too. Although they were always pretty good about allowing patients of private physicians to have access to these studies, which I thought was very noble of them, because they had enough SFGH patients to restrict access to just them. But they seemed to want to have a broad spectrum of various kinds of patients, which was nice.

More on the San Francisco County Community Consortium

Foundation

Hughes: Why don't you tell me how the Community Consortium was founded?

Owen: Donald would be the person to talk to you about that. My understanding is that Mayor Dianne Feinstein had met with a small number of people on a regular basis to discuss AIDS issues in San Francisco. A lot of the discussion initially revolved around the baths, but then it just became a discussion of AIDS concerns in general. And at one point, she mentioned to the physicians there, "Why are you just getting together here? Why don't you get together in some organization yourselves?" And she was surprised to learn that in fact we didn't already have such an organization of AIDS care providers.

And when the physicians, led by Donald Abrams, thought about that, they realized that it's true. We really don't get together as a group. Maybe we should. So that's where the inspiration came from, and the first meetings were held.

University and Community Physicians

Hughes: Were you aware of any tension? My understanding is that academic physicians had pretty much controlled drug trials. [interruption]

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1 See the oral history with Donald I. Abrams, M.D. in the AIDS physicians series.
Owen: I think that that is probably overplayed. I did not really sense any kind of friction there. In fact, I think that one of the promises of this organization was to be all-inclusive, to include practitioners from the community, to include people from academia, to include people from city and county practice, who were also academic as well. But there were various people coming together. And I thought the consortium was a great idea.

When I talk to other physicians from other cities and tell them about our experience, they're so amazed that that can happen and so pleased that it has worked out here. In other cities, that has not happened to the extent it has here. In fact, they say that there are a lot of conflicts and jealousies between HIV physicians in those other cities that would prevent them from even coming together as private doctors, community physicians.

Hughes: Rivalry over patients, you mean?

Owen: Yes, sure. Or just personal jealousies, whatever, let alone coming together with people from the university medical centers.

Hughes: How do you explain the fact that there don't seem to be disruptive rivalries here?

Owen: I'm not sure why that is. Maybe because in the Bay Area--I hate to use the word "laid-back," that's so trite--the physicians are more relaxed about things, maybe not as competitive among practices. Or maybe starting early in the epidemic, working together collegially like that, we never really allowed rivalry to grow.

Hughes: It seems to me a philosophical extension of the so-called San Francisco model, where different agencies were collaborating to provide care for AIDS patients.

Enrolling Patients in Clinical Trials

Hughes: Tell me what actually happens when a physician such as yourself agrees to participate in a community-based trial.

Owen: We're not under any obligation to participate in all of the trials that the Community Consortium offers. We can look them over and pick and choose the ones that we think would be most relevant for our practices. But when we see one that we feel would be useful for our patients, then, of course, we approach the patients who qualify for it. This may vary from trial to trial, but in many of
the trials, we would have them call the research nurse that has been assigned to our practice.

They have a number of research nurses at the consortium, and they divide up the Bay Area and each takes different practices. They essentially try to cluster them for the most part geographically so the nurses don't have to travel too much. Then the nurse would contact the patient and, if it's something simple that could be done over the phone, do it that way; or if it's something more complex that requires a lot of reviewing of documents or more extensive histories, the nurse would arrange to come here at the time of the patient's next appointment and obtain all the necessary information.

The nurses then generally abstract the medical record on a periodic basis to determine all of the necessary information that they need. The laboratory data, the clinical data, is abstracted from the physical examination or history that I take at each visit.

The Consortium's Form for Clinical Trials

Owen: The consortium designed a unique form, which is kind of like a progress record, that has a space for current medications, a space for various reviews of body systems, complaints, fevers, headaches, diarrhea, this sort of thing, and a space for physical examination, and a space to list problems and plans. This is such a very nice, compact form, one sheet, that what we have adopted it to use for all of our patients with HIV. It's very nice because if you need to do a retrospective chart review to find out what is happening with a patient, you can easily flip through that patient's record and see when certain problems began to appear, when and at what point medications were added. It's very nice and compact for chart reviews, and clearer also to doctors who are covering here. So if I'm away and my physician assistant happens to be seeing a patient, he knows exactly where to look on this record to see what's going on with the patient at any given time.

Actually, that form was pioneered in a study that the consortium participated in which was part of the CPCRA, which is the Community Programs for Clinical Research in AIDS. It's a national organization under the National Institute of Allergy and Infectious Diseases, NIAID, one of the NIH branches. That study that we did was called the HIV Observational Database. What it was designed to do was to observe the practice of treating people with AIDS throughout the whole country, so it included all kinds
of different practice settings. They had clinics; they had academic centers; they had private practices.

They computerized it all from those database forms, so they were able to actually look on that database and get interesting information out as it related to HIV treatments from throughout the country. Even though this project has ended, the data repository is still there, and so researchers can go into it and ask questions and try to find some answers.

**Consortium Members: Different Perspectives**

Hughes: At meetings of the County Community Consortium, do the community physicians tend to contribute a certain kind of information, while the health department people have other sorts of things to say, and the university people yet another type?

Owen: Yes. As a matter of fact, in January, one of our Community Consortium discussions dealt with the subject of viral load, and I was one of the panelists. So naturally, my presentation was a much more clinically oriented presentation, how the viral load correlated with clinical applications. There were representatives there from Chiron Company, which is the biotechnology company that makes the branch DNA in Emeryville, and they took more of a research view of that. There was also a physician from the Gladstone Institute of Virology and Immunology, which is the new HIV research institute associated with San Francisco General Hospital, and she took a very basic science view of this. But all together, I think we were able to put together a very interesting panel that had meaning for all the people in the audience.

And by the way, that meeting on that particular subject was the most well attended Community Consortium meeting of any that had ever been held. The room where we hold it at the UC Extension at 15th and Folsom was filled to capacity. In fact, people were sitting on the floor. So it appears that when a topic that is perceived as having great interest to the providers participating in the consortium is announced, our attendance can fluctuate dramatically.

Hughes: How many were at that meeting?

Owen: Oh, I think they said that there were 120 or 130, something like that.

Hughes: What is a more typical number?
Owen: I'd say usually about thirty or forty.

**Parallel Track or Expanded Drug Access**

**Participation**

Hughes: Did you experience parallel track?

Owen: Yes. We participated in those studies from the very beginning. AZT was made available on a phase III clinical study basis. But it was essentially a parallel track kind of thing, because it was done before AZT was approved, from late '86 until spring of '87 when AZT was finally approved. And then the same thing happened for ddc, ddl, and with each of the protease inhibitors. We participated in two of the three protease inhibitor parallel track studies.

One we didn't participate in, which was the Merck one. By this point, the FDA was getting so fast in its drug approval process that it appeared that by the time we got all the paperwork done to participate in the parallel track, the drug would be approved. So our patients on parallel track--or expanded access, as it's called now--would not get their drug until after it was available in the pharmacies. [laughs] So I'm not sure with the way things are going in terms of approval where expanded access is headed. Although it will probably be still around in some form.

**Drugs on Expanded Access**

Owen: For instance, there's a new class of drugs called nonnucleoside reverse transcriptase inhibitors, which includes two drugs, one an Upjohn drug called delavirdine and one a Beringer-Ingelheim drug which is called nevirapine. Those drugs are going to be made available next month as part of an expanded access program and prior to FDA approval. How long they'll be on that until the FDA approves them, we don't know.

We also had expanded access for drugs to treat opportunistic infections--clarythromycin, for instance, the drug I mentioned that we're using to prevent MAC, *Mycobacterium avium* infections. We're also using it now for some rare parasitic infections. We're able to use albendazole from Smith-Kline for microsporidiosis.
There's a new drug now, called nitazoxanide that just became available from a company called unimed. It's used to treat cryptosporidiosis, which is caused by an organism that we're seeming to see more of now, especially in later stage disease, causing severe diarrhea. We haven't really had any effective treatments for that, so we're hoping that perhaps we'll be able to get access to this drug as well.

Advantages and Disadvantages

Hughes: Do you see pluses and minuses to accelerated access?

Owen: Personally, I think I see primarily pluses. I think it allows our patients to have access to the drug at a stage earlier than would be the case otherwise if we had to wait for full FDA approval. Also--this is something I didn't anticipate--it allows us as physicians to get experience with the drug before it's actually out there. We have to fill out these reports, but in the process of doing that, we get a very good feel about the drug, what its strengths and weaknesses are. That's an intangible quality that I think we really hadn't expected.

Hughes: Why is that an advantage? You could say it would be safer if you waited until the drug had been approved, and then, of course, it would be available to you to prescribe.

Owen: Well, I think there's also something to using it in a research mode. You get constant reports back about toxicities that have been reported. You have a chance to report anything that you think is going on. You can really gauge how the drug's working in patients directly, should there be dose adjustments for people. You get a better feel for it than if you're just left with writing a prescription for a drug to be filled at a pharmacy.

Hughes: Did you ever feel that there was a potential conflict when you were doing these studies between your roles as a physician caring for patients and a researcher trying to find out whether this drug was effective?

Owen: Well, in doing this, we're certainly not on anyone's payroll. As a matter of fact, if anything, it costs us money, because we have to have the support staff to be able to do this. One of my arguments, in terms of a negative aspect, is that it's expensive to have to hire somebody. I have an extra person on board probably just to take care of the paperwork that's involved in these studies.
I just record all my observations in the chart on those database progress reporting forms, and the staff person who's assigned to that study is able to abstract the data into the reporting forms. So I think we keep it very fair. I don't think there's any tendency to skew the data. We're trying to be very objective about it. But it's a lot of work, and there's a cost to it. That would be the only negatives that I would see.

Alternative Therapies

Hughes: Do you have a philosophy about the use of alternative therapies?

Owen: I have a lot of patients who do it. In the thorough inventory of medications that I do as part of my regular visit with my patients, I ask them about whether they're doing any type of vitamins, herbs, other alternative therapies. And the patients are very happy to discuss that. Sometimes they won't bring it up first, so they really depend a lot on the provider to ask the question.

Hughes: They think that you will disapprove?

Owen: I think so. When I ask, they realize, Gee, this is something that I can discuss. When they ask me, "What do you think of that?", I have to be honest, however, and say, "Well, I don't know. There aren't any studies on that that I know about. I've had other patients that used alternative therapies and felt that they got some benefit. As long as it doesn't have toxicity associated with it, I don't really mind that you do it. But it's important, obviously, to keep me informed about what you're doing."

Hughes: What about a situation when the patient chooses alternative therapy in lieu of what you might prescribe?

Owen: Well, I've had patients who have done that, and now we have the viral load. We can say, "Let's see if your therapy is really doing anything to the virus." So we can check that and see if in fact it is. Now they want to try curcumin which is an Indian spice--turmeric. If they want to try that, they can get a viral load assessment before they start it, and get a viral load in two to four weeks later, and see if there is any difference. If there is no difference, then they're wasting their time and money.

So now I think we can be a lot more objective about the alternative therapies than we could before. Before, people did them for long periods of time, and there was just really no way to
know whether they were useful or not, and we more or less gauged whether patients would continue them, and the patients gauged whether they felt better—very subjective information.

Hughes: Before the viral load assay, did you feel responsible for trying to persuade a patient who might be on alternative therapy and not taking AZT or whatever that perhaps that was not the best course?

Owen: Oh, of course. We had our guidelines back then for when people should be on nucleoside analogues, and so we would present whatever data we had at the time to the patients. But ultimately, it was really up to them to make the final decision.

AIDS Treatment Activists

Hughes: Did you have any direct dealings with AIDS treatment activists, such as Martin Delaney and John James?

Owen: Well, I'd certainly often meet John James at various conferences. More direct is that a number of my patients over the years have been activists, working at ACT UP [AIDS Coalition To Unleash Power] Golden Gate or in Project Inform. So it's primarily through that route that I have the most familiarity with the activist community.

Hughes: Do you feel the activist movement has been helpful to AIDS medicine?

Owen: Oh, absolutely. I think if it wasn't for that, I don't think the government would have moved as fast as it has in terms of putting money into research. I don't think the FDA would have moved as fast as it has in terms of approval for expanded drug access, and I don't think they would have moved as fast as they have in terms of actual approval of drugs. I think a lot of that movement can be directly attributed to the work of the activist community.

Testifying for Increased AIDS Research Funding, 1983

Hughes: I read that in September 1983, you testified at the annual meeting of the American Society of Internal Medicine in favor of a
resolution to encourage funding for government AIDS research.¹ Do you remember that testimony and how you happened to give it?

Owen: Where did you see that? [tape interruption] I don't remember doing any traveling outside the city to do this. I think they might have had their meeting that year in San Francisco.

Hughes: This is the only information I have, so I can't tell where the meeting was.

Owen: I probably presented it at a hotel downtown. It would be interesting to see how my predictions for the cost of caring for AIDS patients actually stacked up versus the reality of the cost. But even though I might have been off by some numbers, I think that overall, the plea there was for a dramatically increased governmental commitment to the AIDS research effort, compared to what was going on at that time, which was pitifully inadequate. It was only a $40 million commitment at that time, which is pennies in comparison to what is being done today.

I'm glad that we did that and that the American Society of Internal Medicine supported that resolution.

Hughes: Yes, the resolution passed.

Owen: Yes, and hopefully that was one of the factors that contributed to the government actually turning around and putting more money into the AIDS research effort.

Hughes: Was it a receptive audience?

Owen: Yes. The internists there didn't have a lot of experience with HIV, but they were already hearing quite a lot about it through national media. I think that was even before Rock Hudson died.

Hughes: Oh, yes. He didn't die until '85.

Owen: Yes. I think the leak about his disease first came out around '84.

Articles on Care of Patients with AIDS, 1984

Hughes: The following year, you were an author, with Anthony Fauci, Harry Haverkos of the CDC, and Donna Mildvan--is she a New York private practitioner?

Owen: Yes.

Hughes: There were three articles in Patient Care. Is it a standard journal?

Owen: No, it's what we call a controlled circulation journal. What that means is it's mailed to physicians who meet certain criteria. In this case, Patient Care would be for primary care physicians.

Hughes: How did you come to be an author?

Owen: I had been asked to participate in a symposium on gay health care that occurred in 1980. It was the same year that my articles were published in the Annals of Internal Medicine. Patient Care had one of the first roundtable discussions on care of the homosexual patient in that same year. We flew to Chicago and did this with David Kessler. I don't know if you've had a chance to interview him?

Hughes: No.

Owen: He's one of the early pioneers in BAPHR. But anyway, Dave and I were there, along with some other panelists from throughout the country. They ran the articles in three different issues of Patient Care, one with detailed tables about how to treat various sexually transmitted diseases. Another one was on getting to know your gay patients in terms of their emotional status. Dave, being a psychiatrist, was very involved in that one--the clinical approach to the lesbian and gay patient in terms of discussing partners and activities and that sort of thing.

I think it was through that connection that they asked me to discuss this other aspect of AIDS treatment of the gay patient. Now, for this article, as I recall, they didn't call us together in one spot. I think they had separate interviews, including the Bay Area--at least two of the participants were from here. There was a doctor from Berkeley, who was very interested in sexually

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transmitted diseases, that they interviewed as well as myself. The other participants, like Harry Haverkos, were not here.

Hughes: He's at the CDC.

Owen: At the time, yes, and Fauci was with NIH.

Hughes: So the article was obviously written from different perspectives.

Owen: Oh, yes.

Response of St. Luke's Hospital to AIDS

Hughes: You've been associated with two hospitals in San Francisco, St. Luke's and Davies?

Owen: Correct.

Hughes: That gives you some perspective on how hospitals in this city have responded to the epidemic. Could you say something about St. Luke's response? You were there very early in the epidemic.

Owen: 1979 to 1989. St. Luke's is a very interesting hospital. It's an Episcopal hospital, so as a result, they had a mission to help people in need, especially the poor in San Francisco over many years. I think a lot of people there were very supportive of my presence there. I had my office located at St. Luke's. It was a very good ten years that I had there.

A number of the hospital nurses were from cultures where there was really a great deal of phobia about people with infectious diseases, and then especially with the advent of HIV, some degree of AIDS phobia as well. What I did to get around that, because I could sense this with my patients, was on a weekly basis I had a conference, to which I invited the nurses, social workers, dieticians, respiratory therapists, pharmacists, anyone who dealt with my patients on that medical floor, because I had the largest number of people with HIV. Very few of the other physicians at that time had patients with HIV.

It was a teaching conference, and it became a very popular thing. And through that, we really helped sensitize people to our patients with HIV. I think the nurses found it to be a lot less threatening to work with the patients.
Hughes: So it worked both ways: the patients were getting more sympathetic and better care, and the nurses were dealing with their anxieties.

Owen: Right, exactly.

Response of Davies Medical Center to AIDS

Owen: Then in '89, I moved my practice over to Davies, and largely shifted my hospital population over here as well. Well, Davies had been seeing patients with AIDS since the very beginning of the epidemic, being located right in the heart of the Castro.

Hughes: Is that why you moved?

Owen: Yes. It turned out many of my patients, when we did an analysis of their zip codes, lived in zip code 94114, the Castro District and Noe Valley. So it was actually convenient for a lot of them to be over here. Also, my practice was growing; I needed more space. The space wasn't available at St. Luke's. The other thing is Davies had just started an HIV Institute for HIV Treatment and Research, which is headed by Steve Follansbee. He wrote one of the first articles that was published in the Annals of Internal Medicine about Pneumocystis carinii pneumonia. I think he started that when he was a fellow at UCSF, so it was even before he went into practice. The article was published back in '82 in the Annals.

In any event, Steve headed this Institute for HIV Treatment and Research, and it seemed to be a very good opportunity for patients of mine to enter a number of clinical trials outside the consortium and outside the UCSF/San Francisco General trials.

Davies Hospital for a number of years had a unit that was primarily dedicated to HIV care. They even developed an HIV skilled nursing facility. They developed the Gazebo, which is the area between the north and south towers, in which they had day programs for people with HIV, with everything from classes in basketweaving to how to interpret your white blood cell count.

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1 See the oral history in this series with Stephen E. Follansbee, M.D.

So for all these reasons, it was a very attractive place to bring my patients.

Hughes: Are there inpatient and outpatient units?

Owen: Both, yes.

Hughes: How do they compare to those at SFGH?

Owen: Well, I've never actually practiced at SFGH, so it's really hard for me to make that comparison. The person you'd want to ask would be Dr. Follansbee, because he attends at Ward 86 at least one-half day a week or so.

Hughes: Do you work in the AIDS units at Davies?

Owen: Yes. I admit patients to the inpatient unit, the skilled nursing facility. The outpatient unit, the Gazebo, is not a formal provider-involvement kind of unit. It's more an informal, where patients learn about services available to them, hear didactic lectures, for example, about their cell counts, and even engage in crafts, like basket weaving.

Hughes: It's not a clinic per se.

Owen: Right, but patients may sign up for trials there.

Hughes: You're in the clinic, I suppose.

Owen: Davies does not have an outpatient HIV clinic, but it does provide outpatient services, for example, medication infusion and nebulized pentamidine.

Hughes: Are you the private AIDS practice at Davies?

Owen: No, there are a number of practices that have large HIV bases. On my own floor, we have Dr. William Kapla and Dr. Jarom Daszko across the hall. Down the hall we have Dr. Richard Cazen, up the hall we have Dr. Robert Elsen. On other floors, there is Dr. Myles Lippe, Dr. David Drennan, and Dr. Toby Dyner, and her associate, Dr. Larry Price. Those are all gay physicians, and then there are some nongay physicians too who have some fairly large numbers of patients with HIV from just being in this area near the Castro, like Dr. Philip O'Keefe, Dr. Charles Moser, Dr. Stephen Knox. Dr. Knox's former associate, Dr. Patrick McGraw, was gay, but Dr. McGraw retired about a month ago.

Hughes: Is there any competition amongst these AIDS physicians?
Owen: Not really. As the consortium did citywide, I think having the HIV institute here and having monthly meetings—we have an HIV committee here in which most of the practicing physicians participate—led to a sense of collegiality here that you perhaps don't get in other cities.

San Francisco Model Of Comprehensive AIDS Care

Hughes: When people use the term San Francisco model, what comes to your mind?

Owen: When people from [the San Francisco] AIDS Foundation, let's say as an example, have given lectures in other cities telling them how to set things up, they've used that term. What I think of is that care is basically undertaken in both private and public settings in San Francisco, and that cooperation with studies taking place occurs in that care, both through groups such as the Community Consortium and through the university and San Francisco General.

... I don't see people coming on tours any more. It used to be that people came to San Francisco to take tours of the San Francisco model.

Personal Impact of the AIDS Epidemic ##

Hughes: You've been involved in the AIDS epidemic since before it was known as the AIDS epidemic. What has it meant to you?

Owen: Being involved in this epidemic has probably been the most important thing that has defined my career. It's something that I never would have anticipated. After I came to San Francisco and started to do some writing on medical problems on gay men and lesbians, I certainly wanted to have that as an important part of my practice, but I never would have imagined that it would have led to being involved in this worldwide epidemic.

... I think I've made an important contribution, maybe not in terms of being involved in major research projects, but I think in terms of being able to be just a good physician for my patients. I think that I've helped them through the process of their lives and through the dying process. I think I've done a good job in that respect.
It's taught me a lot, too, about what it means to live and what it means to die. The courage of many of our patients has given me a lot more courage in terms of facing life and facing death. I always had fear: how would I face this in my own life? And I don't have that fear any more. I feel that I've been able to assimilate some of the courage that my patients have shown.

Hughes: Well, thank you.
INTRODUCTION


Interview with Robert K. Bolan, M.D.

Interview 1: August 13, 1996
- Tape 1, Side A
- Tape 1, Side B
- Tape 2, Side A
- Tape 2, Side B

Interview 2: August 14, 1996
- Tape 3, Side A
- Tape 3, Side B
- Tape 4, Side A
- Tape 4, Side B

Interview 3: August 15, 1996
- Tape 5, Side A
- Tape 5, Side B
- Tape 6, Side A
- Tape 6, Side B

Interview with William F. Owen, Jr., M.D.

Interview 1: March 27, 1996
- Tape 1, Side A
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Interview 2: April 23, 1996
- Tape 3, Side A
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- Tape 4, Side A
- Tape 4, Side B
APPENDIX--AIDS Community Physicians, Volume III

Curriculum Vitae, Robert K. Bolan, M.D.

Related materials


Brochure, "Guidelines and Recommendations for Healthful Gay Sexual Activity," reprinted by The National Coalition of STD Services, 1981. These guidelines were modified and edited by Doctor Bolan before AIDS was recognized. (Robert K. Bolan papers, AIDS History Project Archives, UCSF Library.)

Brochure, "Guidelines for AIDS Risk Reduction," printed by BAPHR. These guidelines were created and distributed after AIDS was recognized. (Robert K. Bolan papers, AIDS History Project Archives, UCSF Library.)

Memo, from Dr. Marcus A. Conant to the Kaposi's Sarcoma Study group, regarding Kaposi Sarcoma Clinic Meeting, October 14, 1982. (Marcus Conant's Kaposi's Sarcoma Notebook, 3-12/1982, AIDS History Project, Special Collections, UCSF Library).

Press Release, from BAPHR regarding safe sex and the bath houses, April 2, 1984. (Robert K. Bolan papers, AIDS History Project Archives, UCSF Library.)

Correspondence, Dr. Bolan's resignation as president-elect of BAPHR, to the BAPHR board members, April 19, 1984. The BAPHRON 6:7, July, 1984, p. 271.

Correspondence, from Dr. Robert K. Bolan to Dr. James Mason, August 1, 1984. (Robert K. Bolan papers, AIDS History Project Archives, UCSF Library.)
Curriculum Vitae, William F. Owen, Jr., M.D.

Related Materials


CURRICULUM VITAE

A. PERSONAL INFORMATION

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B. EDUCATION

College or University
University of Detroit
Detroit, Michigan
B.S. Biology 1968
With Honors

Medical School
University of Michigan Medical School
Ann Arbor, Michigan
M.D. 1972

Internship
St. Mary's Hospital Medical Center
Madison, Wisconsin
1972-1973
Residency
St. Michael Family Practice Residency
Milwaukee, Wisconsin
1975-1977

Honors and Awards: Leadership Award, San Francisco AIDS Foundation May 1992

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Wisconsin 18349

Board Certification American Board of Family Physicians

C. PROFESSIONAL BACKGROUND
Specific teaching responsibilities:
Associate Professor of Clinical Family Medicine
USC School of Medicine
Department of Family Medicine
September 1995-Present

Assistant Clinical Professor
University of California San Francisco
Department of Family Medicine and Community Medicine
June 1981-Present

Course Organizer and Clinical Faculty
"Clinical Approach to Gay and Lesbian Health Care"
An elective two hour credit course offered by the
University of California, San Francisco Medical School
April 1982-June 1983

Clinical Teaching Faculty
St. Michael Family Practice Residency
Milwaukee, Wisconsin
August 1977-July 1979

Specific administrative responsibilities:
PRESENT
Director of HIV Services
USC School of Medicine
Department of Family Medicine
September 1995-Present

Medical Director
LA Gay and Lesbian Services Center
May 1996-Present

PAST
Acting Chair
Department of Family Practice
California Pacific Medical Center, San Francisco
January 1991-November 1992

Medical Director
Gay Health Clinic
Presbyterian Medical Center, San Francisco
March 1982-June 1983
Attending Physician
Presbyterian Medical Center Clinic, San Francisco
October 1979-August 1980

Hospital Affiliations
USC University Hospital
September 1995-Present

LAC+USC Medical Center
September 1995-Present

California Pacific Medical Center San Francisco
1979-Present

Other Activities
Family Practice
Pacific Family Practice Medical Group
San Francisco, California 1979-September 1995

Family Practice
Hartland Clinic, S.C.
Hartland, Wisconsin August 1977-July 1979

Emergency Medicine
Madison General Hospital
Madison, Wisconsin June 1974-June 1975

Three week intensive post-graduate course in Emergency Medicine
Philadelphia, Pennsylvania April 1974

General Practice
Dells Clinic
Wisconsin Dells, Wisconsin September 1973-June 1974

Emergency Medicine
St. Clare Hospital
Baraboo, Wisconsin June 1973-September 1973

D. SOCIETY MEMBERSHIPS

Local
San Francisco County Community Consortium

National and International
American Academy of Family Physicians

E. ACTIVITIES IN AREA OF INTEREST

Medical Director, Gay People's Union Venereal Disease Clinic
Milwaukee, Wisconsin September 1977-July 1979
Director and Organizer, "Current Aspects of Sexually Transmitted Diseases II", a Symposium, San Francisco State University
San Francisco, California June 1980

Secretary, Bay Area Physicians for Human Rights (BAPHR)
San Francisco, California June 1980-June 1981

Chair, BAPHR Task Force on Kaposi's Sarcoma
June 1981-June 1983

Chair, BAPHR Research Committee
March 1983-June 1983

President-Elect, BAPHR
July 1983-June 1984

President and Chairman of the Board, San Francisco AIDS Foundation
San Francisco, California June 1983-January 1986

Member, AIDS Advisory Task Force of the Director
San Francisco Department of Public Health
San Francisco, California April 1983-January 1986

Member, Mayor's AIDS Advisory Task Force
San Francisco, California January 1985-April 1988

Member, Board of Directors, San Francisco AIDS Foundation
San Francisco, California June 1983-June 1986

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Peer Review

Bolan RK. Homosexual sexually transmitted diseases: focusing the attack. Sexually Transmitted Disease, 8: 293-297, October-December 1981.


Letters to the Editor

G. SCIENTIFIC MEETINGS AND PRESENTATIONS


Guest lecturer, numerous speaking engagements concerning clinical and educational AIDS issues.

Faculty Advisor and lecturer: “HIV/AIDS: What They’re Not Teaching You in School” Student Organization for Medical AIDS Awareness and Los Angeles AIDS Forum, Saturday January 6, 1996. USC School of Medicine

Lecture: “HIV: Early Care” USC Student Health Clinic, February 16, 1996

Workshop: “HIV Risk Reduction and Test Counseling”; Common Problems in Primary Care: 22nd Annual Review Course, April 2, 1996

Workshop: “Managed Care and AETC Training”; Faculty Development Conference, AIDS Education and Training Centers; April 16, 1996; Asilomar

Workshop: “Automated Medical Records, HIV managed care, and Clinical Outcomes Analysis”; 6th Annual Symposium: Clinical Care Options for HIV; May 2, 1996; Scottsdale
New reports on epidemic among gay men

By Richard Saltus
Examiner science writer

A new series of reports on a mysterious and deadly disease spreading among gay men nationwide says that the cause is unknown, but that a prime suspect is sexually transmitted infections that may weaken the body’s natural defenses.

The baffling outbreak may represent a “nationwide epidemic of immunodeficiency among male homosexuals” that leaves them vulnerable to attack by rare “opportunist” infectious organisms, said a report in the New England Journal of Medicine.

Researchers, accordingly, have turned to experimental drugs in hopes of turning the failed immune system back on in patients who have the disease.

Nevertheless, there have been no reported cures and 75 of 180 patients stricken with Kaposi’s sarcoma, pneumocystis pneumonia or both, have died.

And one of the 30 patients in the Bay Area says that despite widespread publicity and concern in the gay community, there has been no radical change in sexual lifestyles or use of drugs, which is another suspected factor.

“I wouldn’t say things have changed much,” said Bobbi Campbell, a nurse who was diagnosed as having Kaposi’s sarcoma in October. “After all, people still smoke.”

The alarming public health problem was discussed yesterday at the 40th annual meeting of the American Academy of Dermatology. Simultaneously, the prestigious New England Journal published three major articles and an editorial on efforts to pinpoint the cause of the outbreak first noticed last spring in New York and, subsequently, California.

Within a few weeks, the Center for Disease Control in Atlanta is expected to reveal what it has found in a computer analysis of interviews with gay men who developed the disease and those who did not.

The hope is that the interviews — 40 were done in San Francisco — will show a pattern of behavior or other factors common to patients afflicted with the disease.

Eight of the 30 Bay Area patients have died.

Dr. Marcus Conant, a University of California at San Francisco dermatologist who heads a special clinic for the disease, said, “We’re advising gay men to try to cut down on the number of sexual partners — ideally to one, rather than 15 or 16 a week.”

But he agreed with Campbell that the gay community has not drastically changed its behavior, and noted that two patients who have the disease have been seen at public baths.

Underlying the disease in nearly all patients is a striking inactivity of the body’s immune system, particularly an imbalance in two kinds of white blood cells that must work in harmony to fight infections.

The patients develop either Kaposi’s sarcoma, an otherwise extremely rare cancer manifest on the skin, or an unusual form of pneumonia, and sometimes both.

Occasionally, people whose immune systems have been purposely “turned down” for organ transplants get this disease, but it rarely appeared in young, healthy people.

What is common to the homosexual patients is that their bodies show signs of infection with a common virus called cytomegalovirus (CMV). The virus can be transmitted sexually, and it has been known to suppress the immune system.

It is therefore highly possible, reported Dr. Michael S. Gottlieb of the University of California at Los Angeles, that sexually active gay men get repeated infections of CMV, perhaps so often that their immune defenses don’t recover from the attacks.

As a result, he said, these episodes “could conceivably lead to overwhelming chronic infection and immunodeficiency or Kaposi’s sarcoma.”

That some individuals contract the disease but most don’t may be partly explained by a current discovery that a high percentage of the patients have genetic similarities in their immune system.

But why, asked the writer of the New England Journal editorial, did the disease appear suddenly?

“Homosexuality is at least as old as history, and cytomegalovirus is presumably not a new pathogen. Were the homosexual contemporaries of Plato, Michelangelo and Oscar Wilde subject to risk of dying from opportunistic infections?” wrote Dr. David T. Durack of Duke University Medical Center.

Conant said it is possible that a new mutant strain of cytomegalovirus has triggered the outbreak, which he said apparently began in New York and may have been spread to San Francisco by gay men who traveled back and forth.

The researcher said some of his patients are being given an experimental drug called thymosine in an attempt to restore the proper balance in cells of the immune system. Patients with the disease have too many cells called “suppressor T-cells” and too few “helper T-cells,” which are supposed to act in concert like the accelerator and brakes of a car.

Thymosine acts on helper T-cells to spur their activity, but Conant said it was too early to tell whether the drug would be effective.

Researchers in New York are giving patients the experimental drug interferon, but the results have been mixed so far, said Dr. Geoffrey Gotlieb, a pathologist from the NYU Medical Center.

Otherwise, patients with Kaposi’s sarcoma are being treated with standard cancer chemotherapy.

The New England Journal editorial called the three reports signed by 30 authors “only a beginning” and urged further research.

Meanwhile, local physicians of the Bay Area Physicians for Human Rights plan to distribute a pamphlet, written in part by Conant, describing the disease and showing pictures so other physicians will recognize it in its early stages.

Dr. Robert Bolan of the human rights group said that some of his patients are becoming “a little more discriminating and more careful.” However, another physician who treats gay patients, Dr. William Owen, said, “My feeling is that a lot of patients are waiting to see if any information can be gleaned as to the cause.”
Sex education is inherently boring I think. In some way or another the message is always: “You shouldn’t _______ because you might get ______.” For some reason the concept of denying a certain, immediate good (sex) because of a potential, delayed evil (disease) has not enjoyed a mass following. Hence we have the school of hard knocks — in which bum fucks soon turn to sores, drips and rashes. Or perhaps an ill-advised slip of the tongue (in cheeks, that is) leaves you bloated and loose of stool with parasites abounding in your bowel. How were you to know?

It’s quite likely that any sex education you had was heterosexually oriented or if related to a Gay sexually transmitted disease was probably after you’d had an infection, and then was presented with thinly veiled contempt or moralistic lectures.

I’m not saying all that is behind us now or that no one is doing anything to make reliable sex education available. However, there is considerable variability in information from one source to the next, sometimes the result of one health professional’s opinions, experience or interests and sometimes the result of incomplete information on the professional’s part.

Fortunately, this country is leading the world with the number of good, Gay-run sexually transmitted disease (STD) services and education efforts are a major part of these services. Knowledge of specific Gay sexual activities, and the ability to be supportive of Gay sexual expression while discussing health and avoidance of disease is absolutely essential if individual health education is to be effective. Therefore, competent Gay input into all sexually transmitted disease (STD) services is necessary for any education effort to work.

In order to take responsibility for one’s choices regarding health, sexually active people must be well informed about: the signs and symptoms of the STD’s, the increased risk factors associated with various sexual practices, and what type of services to request in case there is no access to knowledgeable health providers. Information received from health professionals must be accurate and non-moralistic; facts should be labeled as facts, opinions should be labeled as opinions. Only in this way can Gay people be able to responsibly use the knowledge to alter their risks for disease acquisition and spread.

In an attempt to accomplish this goal, experts in Gay STD’s needed to meet, discuss the issues and come to agreement on the most important information to stress, which misinformation must be corrected, which “popular remedies” might be helpful, which harmful, and which had unknown or unproven effects.

The National Coalition of Gay STD Services (NCG-STDs), now comprising 24 member service groups and 28 individual members nationwide, was formed in 1979 at the first Gay STD medical conference in Chicago. Meet-
ing again in June 1980 at the second Gay STD conference in San Francisco, and again in October 1980 at the American Public Health Association's Annual Convention in Detroit, the NCGSTDs members worked on the development of guidelines and recommendations (G&R's) for Gay people in order to make them more aware of the health risks associated with Gay sexual activity and to suggest ways to minimize the risks of acquiring disease. Dissemination of these G&R's to the Gay community is the responsibility of the NCGSTDs members, so I'm presenting the San Francisco edition. What follows is directed to the Gay male population. Exclusively Lesbian women have virtually no incidence of STD's. This long held impression was recently substantiated by a study in San Francisco.

These G&R's are based on common sense, our current understanding of the occurrence and transmission of infections, and proven data. Occasionally they may represent what is thought to be a good idea but isn't proven. Therefore, the G&R's are subject to modification when new information becomes available.

Although this is not intended to serve as a self-diagnosis guide or a discussion of the specific infections we can acquire sexually, a brief definition of the main infections that will be mentioned follows:

Amebiasis, giardiasis: refers to bowel infection with parasites; usually cause diarrhea, gas, bloating, or alternating constipation/diarrhea; may not cause any symptoms; difficult to diagnose and treat.

Shigella, Campylobacter: refers to bacterial bowel infections; usually quite severe with intense cramping, fever, bloody diarrhea.

Hepatitis A: used to be termed "infectious hepatitis."

Hepatitis B: used to be termed "serum hepatitis" and associated with needle (drug) use; now known to be sexually transmitted and of approximately 8 times higher prevalence in Gay men than straight.

Herpes: a viral infection which can cause recurrent ulcers in the external genital area or, if implanted inside the anal canal, can cause an intensely painful proctitis (rectal inflammation).

Gonorrhea: clap, drip; a bacterial infection which can be in the urethra (penis) where it usually causes symptoms (drip, burning) or in the rectum where it usually does not cause symptoms, or in the throat where it rarely causes symptoms.

Non-gonococcal urethritis: refers to infection in the penis caused by organisms other than gonorrhea.

Non-gonococcal proctitis: refers to infection in the rectum caused by organisms other than gonorrhea.

Venereal warts: refers to warty growths caused by a virus and which may occur on the penis or more frequently in the warm, moist environment of the anus and rectum.

Syphilis: a bacterial infection very common in Gay men; begins as a sore which can be anywhere but usually in the mouth, on the penis, the anus or in the rectum; can cause rash and flu-like symptoms.

One very important fact to understand is that for virtually every STD there are asymptomatic carriers — those who have an infection and are transmitting it to their partners, but who have no symptoms themselves.

Health means much more than the absence of disease and the avoidance of STD's. It is the human condition in which the physical, mental, and spiritual needs of a person are in balance. Healthy sexual behavior is an expression of one's natural sex drives in satisfying, disease-free ways. Guarding your health and respecting the health of your sexual partners means, for one thing, being aware of your body and the messages it may be giving you.

You should routinely examine yourself for any physical signs of infection, such as sores, rashes, or discharges. If you have rectal sex, learning to do a self-rectal examination with your finger while in the shower can be a useful way to discover early any abnormalities such as rectal warts or sores, even before they cause symptoms. Any symptoms such as burning on urination, pain with bowel movements, diarrhea, excess gas, or flu-like symptoms should be acknowledged early and not denied. If a partner mentions that he is just recovering from the flu, it is important to find out what he means by "flu," since it may mean different things to different people. It might indicate diarrhea from amebiasis, giardiasis, bacterial bowel infection, or it might indicate the early flu-like symptoms of hepatitis or secondary syphilis. Virtually any ailment could be the manifestation of a sexually transmitted disease. Therefore, any persistent, abnormal bodily function should be viewed with suspicion. You should abstain from sexual activities if you recognize such signs or symptoms in yourself or in your partners.

Importance of Accurate Diagnosis and Adequate Treatment

Not all diseases have the same treatment. Penicillin does not cure everything. Taking medication only until symptoms go away will not reliably rid you of the infection.

Specific diagnosis of your problem by health practitioners competent in this area of medicine is essential. Many diseases have similar signs and symptoms because the body only has a limited number of ways to respond to the stress of an infection. You will have the best chance of being properly diagnosed and treated if you promptly seek appropriate medical care. Proper treatment also means carefully and completely following instructions for taking medication and avoidance of sexual activities (if so advised) for the duration of the recom
mended time. Take all medication as prescribed because infection may linger and re-occur if you stop treatment as soon as symptoms go away.

The Sexual Encounter

Always exchange your name and telephone number to facilitate contacting case or symptoms of an STD are later recognized or discovered. If your partner does not wish to give you his name and phone number, this is nothing to prevent you from giving him yours — that way, at least you may stand some chance of being notified if he should develop symptoms of something. It is also best to tactfully bring up health before sexual activity begins. If anything suspicious is discovered you might want to make this just a friendly meeting without sex and postpone the intimacies until later when the problem is resolved. When you do go to bed with someone, undressing in a lighted area will allow you to casually inspect for growths, sores or rashes, especially around the genitals. If no reasonable explanation is given, postpone the encounter. You might incorporate showering together before sex into your foreplay, that way you can wash and casually examine at the same time.

Hygiene

Medical opinions differ on the value of washing the genitals and anus with soap and water before and after sex to reduce the incidence of STD's. Although not proven, it is generally believed that washing of the genitals and anus may decrease the risk of acquiring certain diseases such as the bacterial bowel infections (shigella and campylobacter), hepatitis A, amebiasis, giardiasis and pinworms.

Similarly, it is thought that urinating after sex may reduce the risks for acquiring gonorrhea and nongonococcal urethritis. Again, there is no evidence to support this. The role of inserting antibiotic solutions, soaps or other agents into the urethra (the urinary opening) is not at all known and may be hazardous.

Many think that rectal douching (with tap water) is an effective preventive measure against infection. In fact, there is evidence to suggest that it may actually increase the risk of some infections. Douching just prior to sex may alter the rectal mucous membrane barrier function and make the passage of the hepatitis B virus into the body easier; if one has an amebic bowel infection, douching may actually bring more infectious amebic organisms down into the rectum and around the anus, thus making you more likely to spread the infection to your partner.

Scented lubricants may cause a chemically induced proctitis (rectal inflammation), therefore the use of hand lotions and other scented products for these purposes are discouraged. In addition, the use of saliva as a lubricant may introduce other infections into the rectum.

It is not known whether the following measures have any role in reducing the acquisition or transmission of the STD's: hydrogen peroxide or other mouthwash gargling to control oral gonorrhea; soap instilled into the end of the urinary opening to control gonorrhea and nongonococcal urethritis; antibacterial creams, lubricants, suppositories for inserting into the urethra or rectum; water soluble vs. edible vs. petroleum lubricants (e.g., KY vs. Crisco/Lube vs. Vaseline) for rectal intercourse.

The use of condoms (rubbers) for anal intercourse will protect against the spread of syphilis and gonorrhea and may even offer protection against herpes, hepatitis B, nongonococcal urethritis and proctitis (these latter four claims are not proven). High quality condoms should be used since breakage may occur more frequently with anal intercourse than with vaginal intercourse.

Sexual Practices

Many factors must be considered when determining a person's risk for acquiring or transmitting any STD. Six major categories are listed below, describing the relative risk as high, medium, or low.

1. Frequency of sexual contact. High risk: more than 10 different sexual partners per month; Medium risk: between 3-10 different sexual partners per month; Low risk: less than 3 different sexual partners per month.

2. Type of sexual encounter. High: primarily one time, anonymous encounters; group sex; Medium: several times with the same person over a period of time; sex within a small group of friends; Low: primarily monogamous sex for both you and your partner.

NOTE: Anonymous sex makes interruption of the chain of disease transmission almost impossible and it is one of the most important reasons for the high prevalence of STD's in Gay communities. But for the individuals, anonymous sexual contact for the person discovers an infection shortly after your meeting. It is not likely that you will know much about your anonymous partner, such as his recent health, the number of different sex partners he had recently — in other words, his risk profile is largely to be unknown to you than partners in the medium and low risk categories.

3. Place of sexual encounter. High: bathhouses; bookstores; Medium: public restrooms; parks; bars; motor vehicles; Low: private homes.

NOTE: Risk in this category is based largely on the number of contacts per visit, the likelihood of anonymity, and probably also because of incomplete or no cleansing between contacts. Assuming that bathing the anal and genital areas is helpful in reducing some infection spread, the "safest" place to meet someone at the baths is in the shower.

4. Drug use.

NOTE: Generally accepted medical opinion is that use of mood or consciousness-altering drugs (alcohol — alco-
hol, cocaine, valium, Quaaludes, etc.) that are affecting you while you are having sex may alter decision-making abilities about sexual activities practiced, having sex with more people, etc. Drug use becomes particularly dangerous with the use of toys, dildoes, and fist fucking; sensation of pain may be significantly diminished with chemicals (including poppers) so that injury may occur.

5. Geographical area where you and your partners live and have sex. High: New York City, Los Angeles, San Francisco, Chicago, foreign countries; Medium: other large urban areas; Low: small cities and towns, or rural areas.

6. Types of sexual activity practiced. High: active or passive rectal (fucking or getting fucked); rimming (asshole licking, oral/anal); scat (eating shit); fist fucking. Medium: active or passive oral (the one doing the cocksucking has a greater chance of getting something than the one being sucked); Low: masturbation only (J/O); body rubbing; water sports.

NOTE: Major surgery may be required to repair injuries sustained from fist fucking; any type of oral-anal-rectal contact carries a very high risk (in some places like San Francisco, the risk almost approaches certainty) for acquiring hepatitis A, hepatitis B, amebiasis, giardiasis, shigellosis, campylobacter. Another important aspect about fecal-oral contamination is that you don't have to rim someone to rim him. In a bathhouse or other setting in which numerous sexual contacts per visit is the rule, if you suck a cock that has fucked someone with little/no bathing in between — Voila! And happy "indirect" infection! Also, roving, probing hands and fingers will spread potentially infectious material to other parts of the body where mouths and tongues will pick it up.

Rimming except in an exclusively monogamous relationship should be eliminated from the activities of everyone who is not interested in getting amebiasis, giardiasis, shigellosis, campylobacter bowel infections or hepatitis A or B. Those who have a stable, but open relationship allowing for outside contacts, and who enjoy oral-anal stimulation could limit this activity only to their primary relationship and thus decrease their risk from "outside" infection.

It is through getting fucked that you have the highest risk for acquiring hepatitis B; fucking (being the "active" partner) is also a risk for hepatitis B but less than being fucked. Oral-genital and oral-oral contact is not associated with hepatitis B.

By getting fucked you can get rectal gonorrhea, rectal herpes, syphilis, nonspecific proctitis (rectal infection from other organisms), and rectal warts. Rectal tissues and tears can also result.

In oral sex (cocksucking), gonorrhea and syphilis are the most likely infections to be transmitted. It is very unusual to get urethra gonorrhea from having your cock sucked by someone who has pharyngeal (throat) gonorrhea.

**Bathtouses**

Batthouse managements are asked to print up cards and/or matchbook covers to enable patrons to exchange names and phone numbers. The local VD clinic phone number should also be imprinted there, and also prominently posted on bathroom walls with slogans encouraging frequent VD testing and showering after each sexual encounter. Bathtouses are encouraged to exchange all soiled towels for free to allow for frequent showering and washing. On site testing for STD's at the bathtouses could be done by trained and supervised batthouse employees. (Probably only syphilis and gonorrhea testing would be practical.) Management may further offer an incentive for onsite VD testing by offering free or discount locker passes (for the patron's next visit), free coffee, or membership reduction (4-5 onsite tests within a year might be the qualifying number).

**Routine & Regular VD Testing**

Routine VD testing should include a VDRL or RPR blood test for syphilis and tri-stie gonorrhea cultures (oral, urethral, and rectal), and preferably a rectal examination. Rectal cultures and rectal exams are not needed if you have no rectal sex. A first voided morning urine specimen for detection of urethra gonorrhea may be substituted for the usual swab culture if practical and possible in the health care setting you attend. Currently there are no easy, efficient diagnostic procedures for amebiasis and giardiasis, therefore routine asymptomatic (no symptoms) testing cannot be feasibly accomplished. Hepatitis B antigen and antibody and hepatitis A antibody testing is encouraged so that you will know if you are susceptible or immune to hepatitis. (You may have already had either infection without your knowledge and without symptoms of illness, and if you have your body might have made protective antibodies against the viruses, therefore giving you immunity to reinfection.) Hepatitis B vaccine will be available shortly and should be received by all those who have no antibodies against hepatitis B.

Frequency of VD testing depends on the risk factors associated with sexual activity discussed above. Monthly testing is urged for those at high risk; testing every three months is recommended for those at medium risk; semiannual or annual testing is recommended for those persistently at low risk. If in doubt, or if symptomatic, get checked immediately! The doctor or testing facility you visit, even in San Francisco, may not offer adequate screening if they are not familiar with your sexual lifestyle and practices; therefore, it is imperative that you learn what types of testing are necessary for you.

Robert K. Bolan, M.D.
General/Family Practice, San Francisco; Member, National Coalition of Gay STD Services, Bay Area Physicians for Human Rights.
GUIDELINES FOR AIDS RISK REDUCTION

What is AIDS?

- AIDS is shorthand for Acquired Immune Deficiency Syndrome
- AIDS is a disease that damages the immune system of otherwise healthy persons
- AIDS is a life-threatening disease
- AIDS may be a sexually transmissable disease

The message is clear:

AVOID THE DIRECT EXCHANGE OF BODILY FLUIDS.

Strong evidence indicates that AIDS is transmitted by direct contact with the bodily fluids of a person who is infectious. The most common way in which bodily fluids (semen, saliva, urine, blood, and even stool) are exchanged is through intimate sexual contact.

As with other sexually-transmitted diseases like gonorrhea, syphilis, hepatitis, herpes, etc., it may take only ONE contact to acquire AIDS.

WHAT HAPPENS TO PEOPLE WITH AIDS?

They are susceptible to a wide variety of illnesses which are neither "new" illnesses nor unique for AIDS patients. These include serious infections caused by some microscopic parasites (e.g., pneumonia caused by Pneumocystis carinii), some bacteria (including one related to the agent of tuberculosis), some fungi (e.g., cryptococcal meningitis), and some viruses (e.g., prolonged herpes rectal ulcers). Certain cancers, particularly Kaposi's sarcoma, have been the major manifestation of AIDS in many individuals. Not all people with AIDS get all these diseases.
BUT WHAT ARE THE SYMPTOMS OR SIGNS OF AIDS?

Many symptoms associated with AIDS are nonspecific and can occur with benign ailments such as a cold, bronchitis, or stomach flu. What characterizes many AIDS symptoms are their duration (much longer than harmless, self-limited conditions), their unrelenting waxing and waning, their severity, and frequently their coexistence with an increasing debility or failure to thrive.

General symptoms of AIDS may include the following:

- Unexplained increasing and persistent fatigue.
- Periodic or regular fevers, shaking chills, drenching night sweats not accompanied by a known illness and lasting longer than several weeks.
- Weight loss that is unexpected and greater than approximately 10 lbs. in less than 2 months.
- Otherwise unexplained swollen glands (enlarging lymph nodes with or without pain, usually in the neck, armpits, or groin) lasting for more than two weeks.
- Pink to purplish flat or raised blisters or bumps, usually painless, occurring on or under the skin, inside the mouth, nose, eyelids, or rectum. Initially they may look like bruises that do not go away and they usually are harder than the skin around them.
- Persistent white spots or unusual blemishes in the mouth.
- Persistent or often dry cough that is not from smoking and has lasted too long to be from a usual respiratory infection.
- Persistent diarrhea.

If you are uncertain about your health, please see a health care provider knowledgeable about AIDS and its manifestations.

HOW IS AIDS CONTAGIOUS?

This answer requires some understanding of general principles that apply to all contagious diseases. In general, disease transmission requires a vehicle carrying a significant number of germs into a susceptible person. A vehicle can be microscopic amounts of blood such as in the case of some types of hepatitis. It can be urine or semen in the case of cytomegalovirus (CMV). It can be pus or stool or the objects contaminated with these. Not all germs are present in all body fluids or secretions.

HOW ARE WE SUSCEPTIBLE TO INFECTIONS?

We are susceptible either by 1) exposure to germs that are very invasive and that respect none of the natural barriers most people have, or 2) damage to natural barriers allowing invasion of germs that otherwise might not have a chance to cause infection.

WHAT ARE THESE NATURAL BARRIERS?

They include intact skin and mucous membranes of the nose, throat, urethra, and rectum. They include stomach acid which kills many swallowed germs. They include healthy cells of the nose and lungs which can filter and expel inhaled germs. They include normal mucus and saliva production which can coat and "neutralize" many germs.

ARE THERE ANY OTHER BARRIERS BEHIND THE NATURAL ONES?

A hand can be held over the mouth when coughing, a tissue or handkerchief can be held over the mouth when sneezing, a condom can be used when having sexual intercourse with a man. These and other means of avoiding direct contact with the excretions and secretions (urine, stool, blood, semen, saliva) of other persons represent barriers that limit the chance for you to acquire germs those people may harbor—even if they don't appear ill.

YOU MEAN I CAN CATCH AN INFECTION FROM SOMEONE WHO DOES NOT APPEAR ILL?

Yes. Many infections are contagious even during the incubation period. This means that during that time after a person is infected but before he or she feels sick, the germ for that illness may be transmitted to other people. It is proposed that the incubation period for AIDS may be 7-24 months or longer. Thus, there may be two years or more between the time the person is infected and he feels sick with AIDS. It is therefore possible and probable (but not proven) that the AIDS agent may be spread during this time.

WHAT DOES ALL THIS HAVE TO DO WITH AIDS?

As stated earlier, no one knows if AIDS is caused by a germ. If it is, we do not know (1) what the vehicle(s) is/are that carries it, (2) how many germs it takes to cause disease, (3) whether all people who come into contact with the germ are equally susceptible to its consequences, or (4) how long the infectious period may be. We also do not know if there are other factors that make an individual particularly susceptible to the disease.
The following items are important factors for spread of sexually-transmitted diseases in general, their possible correlation with AIDS is based on the increased likelihood of acquiring a theoretical AIDS germ.

- Anonymity: Anonymity in reference to sex is a relative term which includes those sexual encounters where you know nothing or almost nothing about your partner's health, frequency of different sex partners, and sex or health practices. In other words, you have no chance of knowing how likely it might be for that person to harbor an infection that you might acquire. There are obviously varying degrees of anonymity: the encounter where you only ever see one area of your partner's anatomy; the "one night stand" with whom you have spent some time and have established some rapport, and so on. Although far from foolproof, knowing a person's habits and self-care will give you a much more accurate estimate of his health.

- Bathhouses, back rooms, bookstores and parks: Places where one is quite likely to have sexual contact with more than one partner at a visit or more than one partner at a time represent increased opportunity for transmitting infections. This is particularly true when facilities for hygiene are either absent or inadequate.

- Drugs: Although no studies to date have singled out any drug as a significant risk for AIDS we think that the use of mind altering drugs can affect many aspects of overall health by impairing sleep, causing a "drugged" or non-natural sleep, affecting decisions about the kind of sex one has, the number of partners one has, and altering pain appreciation so that injury may occur.

Ideally, our sexual practices will be both fun and healthy. If you determine that some changes are needed, additional things worth considering follow:

- If you choose not to eliminate something that may be risky, consider modification. For example, if you wish to continue bathhouse partners, consider not having rectal sex with them.

- Recognize that some of the advised changes may go against current subculture sexual customs so that peers may not readily accept your decisions.

- The freedom to discuss sexual preferences openly with partners provides the needed opportunity to include communication about sexual limits.

- Fantasy will always be a central feature in human sexuality, so that if you choose to eliminate a particularly favored but risky activity, fantasize about it.

- Take good care of your body and general health (adequate rest, good nutrition, physical exercise, reduction of stress, reduction of toxic substances — alcohol, cigarettes, marijuana, poppers, non-prescription drugs).

- Consider showering before sex and inspect your partner.

**REDUCING RISK**

Reducing risk for AIDS may mean making changes in sexual practices but it does not mean denying the sexual part of one's life. Fear of AIDS can and probably will stir homophobic responses in many of us.

Gay sex and intimacy with gay men may be seen as bad and to be avoided at a time when we need more intimacy and self-affirmation. We may need to create a kind and rational "gay parent" in our heads that counteracts such negative thoughts and guides us toward a healthy regard for our bodies and the bodies of those we love. However, we urge careful consideration of the following points and their implied suggestions.

There are general factors agreed upon by virtually all researchers as representing significant risk:

1. Sexual activity in which bodily secretions are exchanged;
2. The more partners with whom sexual activity includes secretion exchange, the greater the risk.
3. The injection of illicit drugs or the shared use of needles for such injections. By logical extension, sexual contact with those known to use intravenous drugs would represent significant risk.

Certain sexual practices are known to be associated with an increased risk of sexually transmitted diseases. Unless you and your partner have been monogamous for two years or more, eliminating, reducing, or modifying these practices may decrease your risk for AIDS. Remember the principles of protective barriers and blocking the spread of germs in blood, secretions and excretions from person to person.

- Fisting (both giving and receiving): With the microscopic and frequently visible injury to the rectal tissues, germs may penetrate into the bowel and bloodstream; also the inserting partner's fingers or hand is exposed to all the bowel germs and with the tissue injury involved, is exposed to his partner's blood. This is one practice for which correlation with AIDS has been demonstrated.

- Oral-anal contact (rimming): The "active" partner is at risk of ingesting multiple infectious agents in feces; the receptive partner may absorb his partner's saliva into his bloodstream through small tears or fissures in the anal skin.

- Anal intercourse receptive (being fucked): This is another practice for which AIDS correlation has been shown. Because the rectal lining can be easily injured during anal intercourse, foreign material or germs in your partner's semen can gain direct access to your
bloodstream. The use of condoms for intercourse would provide the logical barrier to reduce the likelihood of this happening. If a condom is not used, withdrawal prior to ejaculation would be a "next best" precaution. Since inanimate objects not only can induce tissue injury but can carry germs, using only your own douche equipment or toys is prudent.

- Anal intercourse insertive (fucking): It is not certain whether significant trauma regularly occurs to the penis during anal intercourse so that infections can enter the bloodstream. However, use of a condom will protect the wearer against many of the sexually transmitted infections.

- Note: Lubrication for anal intercourse is important. Saliva, though ever-present, is a poor lubricant. First, it is loaded with germs from the mouth; second, its ability to reduce friction is very short lived. Thus, tissue injury results more readily and this enables those mouth germs to gain entry into the bloodstream. The best lubricant should be non-perfumed and in closed containers which can't be contaminated with fecal germs to be transmitted to the next partner.

- Oral-genital insertive (being sucked): If there are no cuts or abrasions on your penis to be infected by mouth germs, probably no extra precautions need to be taken except to avoid trauma done by the teeth.

- Oral-genital receptive (sucking): With the intact barriers of unbroken skin on your partner's penis and your unbroken oral mucous membrane, this activity probably presents minimal risk. Remember that semen is a bodily secretion that may contain germs or other material foreign to your body. Either not having your partner cum in your mouth or not swallowing the cum are ways to minimize your exposure. If there is uncertainty about the recent whereabouts of your partner's penis, requesting a shower never hurts.

- Water sports: Urine on an intact skin probably represents little risk but when it enters the body it becomes the exchange of an excretion.

- Kissing: Providing neither partner has open cuts or sores of the mouth, lips or tongue, kissing probably represents little risk. Although the degree of infectivity of saliva by the various routes of access into the body mentioned above are not known, it is unlikely that an AIDS agent could be transmitted easily through kissing.

- Hugging, cuddling, sensual massage, mutual masturbation: Since no bodily fluids are exchanged, these activities are sexual, offer no risks for AIDS transmission and could easily be encouraged.

**SOCIAL AND COMMUNITY RESPONSIBILITY**

The uncertainty about AIDS will be overcome. In this health crisis there are the seeds for positive social growth. We think that thoughtful consideration of the facts will help achieve:

- Recognition of our fear through a sharing of feelings with partners, friends and strangers in discussion groups and other organized efforts and hopefully the channeling of those fears into effective action.

- Emotional and financial support for those who have or who are suspected of having AIDS.

- A community network that provides a supportive atmosphere in which the principles in these guidelines can be accomplished.

- A community that assists anyone affected by AIDS or AIDS-like conditions to maintain intimacy and sexual contacts without risking their health or the health of their partners.

- A knowledge of AIDS based on fact and not on rumor.

- Continued development of gay-influenced support, education, referral services, and research (SHANTI and AIDS-KS Foundation).

As we offer these guidelines, we are actively working to marshal the energy and funds necessary to solve this health crisis as soon as possible.

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This brochure was prepared by the BAPHR Scientific Affairs Committee with invaluable counsel of many gay community leaders.

For referral service, call:

**BAPHR** — (415) 673-3189

**AIDS-KS Foundation** — (415) 866-4376

For reprint requests, contact:

Bay Area Physicians for Human Rights
P.O. Box 14546, San Francisco, CA 94114
TO: Kaposi Sarcoma Study Group
FROM: Dr. Marcus A. Conant
RE: Kaposi Sarcoma Clinic Meeting--October 14, 1982

The Kaposi Sarcoma Clinic will meet at the usual time in the Dermatology Clinic on Thursday, October the 14th, at 11 o'clock.

At our last meeting, we began the discussion of the type of advice which should be given to patients suffering from Kaposi's sarcoma--regarding their sexual activities and things that they can do to improve their immune system. We would like to continue this discussion with Dr. Robert Bolan and other physicians from the community, and extend the discussion to the significance of the Helper:Suppressor studies in apparently healthy gay men.

PRESS RELEASE - FOR IMMEDIATE DISTRIBUTION

April 2, 1984

Recently, there has been some confusion in parts of the press and the public regarding the official position of the Bay Area Physicians for Human Rights (BAPHR) about sexual activity at gay bath houses and similar establishments during the AIDS crisis.

We wish to restate our opinion that certain types of sexual practices, no matter in what location they occur, increase the risk of contracting all sexually transmitted diseases, including AIDS. What counts is what you do, not where you do it.

We continue to discourage unsafe sex practices in all areas, including bath houses.

We strongly favor, and request assistance for, educational programs to help reduce risks. Furthermore, we think that such efforts may be especially significant at bath houses and similar establishments.

We affirm our belief that government intervention in the sexual behavior of consenting adults should be avoided.

Most importantly, we believe that voluntary action by our community is the best method to encourage safe sex. In these difficult times, let us act with concern and responsibility for each other.
Apology

The letter of resignation by Doctor Bolan as President-elect was inadvertently omitted from the June Baphron. The editors regret this error and apologize to Doctor Bolan and the membership.

April 19, 1984
Kent Sack, M.D.
President, BAPHR

Dear Kent and members of the Board,

It is with great regret that I notify you of my resignation as President-Elect of BAPHR.

I have spent several long, arduous weeks grappling with this issue, weeks that have also been filled with the continuing drama of the AIDS crisis. During this time I have reviewed my nearly five year intense involvement with this noble organization, the status of my practice and my relative lack of involvement with it, the status of my relationship with my lover, and my personal, professional, and financial goals.

As President of the San Francisco AIDS Foundation, the past year has been a particularly difficult but instructive one. I have had the opportunity to experience being the head of a complex community organization that has multiple levels of responsibility and input. From what I have observed in all of the previous BAPHR Presidents, their time commitments have been roughly the same as mine this past year.

Being a primary care practitioner with the ultimate medical responsibility for the daily care of an ever increasing patient load of men with AIDS, ARC, lymphadenopathy, anxiety and depression, I find my personal and professional resources are being increasingly challenged. The knowledge base needed for the proper care of these patients is ever expanding and it takes time to acquire and constantly rearrange this information. I do not currently have enough time to devote to study and I must recognize this as my primary professional priority.

Succinctly stated, neither my practice, my relationship, nor my person can withstand another year of these intense commitments. Each of these areas of my life have suffered significantly and I must now turn my full attention to them and their nurturing.

I wish I had had the common sense to recognize my limitations earlier and see the signs of impending burnout so that I would not now be altering the smooth BAPHR plan for officer succession. But it is far better to stop this way, at this time, than to push forward knowing that the fire has gone out of my belly and that I was driving myself and possibly BAPHR to ruin.

There is time to find a suitable replacement for Kent, and I will help in that process.

Respectfully,
Robert K. Bolan, M.D.

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Gonorrhea Statistics
San Francisco City Clinic

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1984

| 1st | January | 31 | 400 | 1.00 |
| February | 44 | 444 | 1.52 |
| March | 28 | 472 | 0.90 |
| 2nd | April | 39 | 511 | 1.30 |
| May | 38 | 549 | 1.22 |
| June 1-15 | 14 | 563 | 0.93 |

AIDS Statistics
San Francisco

John Russell to Head Social Concerns Committee

John Russell has been appointed as chairperson of the social concerns committee by President Kent Sack. This important committee coordinates such activities as the gay freedom day parade at BAPHR booth, the booth at the Castro Street fair, the Health Fair, and other special events and issues in which BAPHR is involved. Anyone who wishes to join the committee should contact John through the BAPHR office. Will Willner resigned because of his illness.

---

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INVESTMENT SECURITIES

James E. Mock
Vice President

(415) 566-8634

10 Loma Vista Terrace, San Francisco, California 94114
August 1, 1984

James O. Mason, M.D., Dr.P.H.
Office of the Director
Centers for Disease Control
1600 Clifton Road
Atlanta, GA 30333

Dear Dr. Mason:

Although we seem to be making important strides in basic science AIDS research I think it is generally understood that "vaccine" or "cure" are not tools we can expect to hold in our hands for many years. That leaves AIDS prevention programs as the only way we can hope to have an impact on this disease. For the largest at risk group, homosexually active men, this means behavioral change.

For some time we have been struggling with "high risk" education in our communities through the energetic efforts of many in organizations such as Gay Men's Health Crisis in New York, San Francisco AIDS Foundation, Bay Area Physicians for Human Rights and American Association of Physicians for Human Rights to name a few.

Obviously the main educational problem is our inability to give a clear message about what specific sexual behaviors carry how much risk. The dismally small number of behavioral epidemiological studies to date support only increasing numbers of different sexual partners as presenting clear risk. The profusion of "high risk" literature across the country speaks with many voices about definitions of risk. It is no wonder that the study groups being conducted by the San Francisco AIDS Foundation are finding that those men who have changed their behavior have more consistently reduced the numbers of partners rather than changed specific behaviors. We have been able to speak uniformly about numbers and that message has been received. Review of the health education literature supports this observation---when a health message contains qualifiers (or is inconsistent from one source to the next), compliance plummets.

Another problem in AIDS risk reduction has been the lack of a systematic approach in examining the homosexually active male at risk subpopulations for the various determinants of sexual behaviors. An early assumption (understandable I suppose) was that a "one message for all" approach would be sufficient. Then we fell prey to two other fallacies; a.) the assumption that selling health messages is merely a variation on selling soap, i.e., a flashy, hi-tech ad campaign will be successful if you
just get the best firms and spend enough money, and b.) that
the expertise for developing the messages was readily available
through anecdotal observation of the at risk communities by
those who were "insiders". It is the final laying to rest of
the latter two fallacies that I owe to Marshall Kreuter and
the team from the Division of Health Education who took the
recent AIDS Health Update on tour. My literature reviews in
health education had convinced me by that time that even by
using the most current health education theories there wasn't
much promise or direction in mapping a strategy for AIDS education
programs. The PRECEDE model as described by Larry Green, Marshall,
et al. is, I think, the appropriate tool to critically examine
popular biases, weigh them, draw out more incisive observations,
and then select from them the most likely determinants of at
risk behaviors in different subgroups, rank them in terms of
changeability and importance and then target messages through
appropriate media in a preplanned direction. Done in this way,
such programs are evaluable and hence exportable to other locales
(at this point my strong bias is that communities with differing
disease prevalence and different acceptance of homosexuality
will have different social and health priorities).

I am firmly convinced that people like Marshall, Rich Needle,
Michael Gorman, Fred Kroger form the nucleus of one of CDC's
most important AIDS activities. AIDS Prevention Programs from
now on must be based on knowledge of the target populations,
knowledge of what works in health education, and knowledge of
strengths and weaknesses of the media—in short, it must be
firmly based in the social sciences.

I am excited about the broad based team of consultants I have
assembled at the San Francisco AIDS Foundation comprising the
disciplines of epidemiology, education, psychology, market research,
advertising, administration, clinical medicine, and sexology.
Marshall has met this group recently and his consultation helped
to importantly solidify and focus the group on the task at hand
and the broader federal picture that was possible. I believe
we are on the cutting edge of this most challenging and critical
social and health issue. We need support from the CDC and I can
think of no better way to channel it than by making the DHE
responsible for allocation of federal funds earmarked for AIDS
Prevention Programs.

I am most interested in your comments and suggestions.
It is easiest to reach me through my office: 2252 Fillmore Street,
San Francisco, CA 94115; phone: (415) 921-5762.

Sincerely,

Robert K. Bolan, M.D.
President, San Francisco AIDS Foundation
CURRICULUM VITAE

William F. Owen, Jr., M.D.

Office Address
45 Castro Street, Suite 402
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Office Telephone
(415) 861-2400

Date of Birth
February 24, 1949

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Philadelphia, Pennsylvania

Citizenship
U.S.

Education
Temple University
Philadelphia, Pennsylvania
1965-1969
Bachelor of Arts Degree cum laude, 1969

Temple University School of Medicine
Philadelphia, Pennsylvania
1969-1973
Doctor of Medicine, 1973

Baystate Medical Center
An Affiliate of Tufts University School of Medicine
Springfield, Massachusetts
Residency in Internal Medicine, 1973-1976

University of California San Francisco
San Francisco, California
Fellowship in Emergency Medicine, 1976-1978

Positions Held
Coordinator of Emergency Medicine Education, 1978-1979
University of California San Francisco
San Francisco, California

Private Practice, 1979-present
Internal Medicine and Immunodeficiency Disorders
San Francisco, California
Licensure and Certification

Medical Licensure:
California G-031385

Specialty Certification:
Diplomate, American Board of Internal Medicine, 1976

Professional Associations

American Medical Association
California Medical Association
San Francisco Medical Society
American Society of Internal Medicine
California Society of Internal Medicine
San Francisco Society of Internal Medicine
Union of American Physicians and Dentists
American Medical Informatics Association
American Venereal Disease Association
International AIDS Society
International Association of Physicians in AIDS Care
Community Consortium on AIDS of San Francisco
Gay and Lesbian Medical Association
(formerly American Association of Physicians for Human Rights)
Bay Area Physicians for Human Rights
   Founder: 1977
   Secretary: 1977-1980
   Member: 1977-present

Hospital Affiliations

Active Staff
Davies Medical Center
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San Francisco, California 94114
### Associate Staff
St. Luke's Hospital
3555 Army Street
San Francisco, California 94110

### Civic and Political Activities
Human Rights Campaign

San Francisco Personal Computer Users Group

### Other Professional Activities
Member of Board of Consulting Editors, *Journal of Homosexuality*
1984 to present

Consultant to Task Force on AIDS, California Medical Association
1982-1989

Member of AIDS Medical Advisory Committee, Department of Public Health, City and County of San Francisco
1986-1988

### Honors and Awards
In 1982, the University of California, San Diego designated the first clinic in the San Diego area to serve the health needs of gay and lesbian patients as “The Owen Clinic” in honor of William F. Owen, Jr., M.D.

On October 13, 1988, at its Annual Meeting in Atlanta, Georgia, the American Society of Internal Medicine named William F. Owen, Jr., M.D. as the recipient of its 1988 Special Recognition Award, in honor of his work with patients with human immunodeficiency virus.

### Biographical Directory Listings
Directory of Medical Specialists

American Board of Medical Specialties
Directory of Certified Internists

Who's Who in California
Publications: Peer Reviewed Journals

Owen WF Jr.
Sexually transmitted diseases and traumatic problems in homosexual men [Review].

Owen WF Jr.
The clinical approach to the homosexual patient.

McGhee RD, Owen WF Jr.
Medical aspects of homosexuality [letter].

Bolan RK, Owen WF Jr, Owen RL.
Hepatitis B and sexual practices [letter].

Owen WF Jr.
Sexually transmitted diseases in the homosexual community.

Owen WF Jr.
Medical problems of the homosexual adolescent.

Owen WF Jr.
The clinical approach to the male homosexual patient.

Bush RA Jr, Owen WF Jr.
Trauma and other noninfectious problems in homosexual men.

Owen WF Jr.
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Tolerability of combined ganciclovir and didanosine for the treatment of cytomegalovirus disease associated with AIDS.  

Lalezari JP, Drew WL, Glutzer E, Miner D, Safrin S, Owen WF Jr, Davidson JM, Fisher PE,  
Jaffe HS.
Treatment with intravenous (S)-1-[3-hydroxy-2-(phosphonylmethoxy)propyl]-cytosine of acyclovir resistant mucocutaneous infection with herpes simplex virus in a patient with AIDS.  
Let's submitted for publication must be typed double-spaced. Text length must not exceed 500 words, and no more than five references, at least five references must be furnished, as specified in "Information for Authors" (page 1-6). Specific permission to publish should be appended as a postscript. Publication depends on availability of space. We give preference to items on recent content and new information. Letters for this section should be concise, the Editor reserves the right to shorten them and make changes that accord with our style.

Hepatitis B and Sexual Practices

To the Editor: Reiner and coauthors (1) present evidence for de facto parenteral transmission of hepatitis B through specific sexual activities in gay men and provide more information on the complex puzzle of disease and data collection in this population. We present four points for consideration.

First, in a study of sexual transmission of hepatitis A, Corey and Holmes (2) found the acquisition of hepatitis B significantly correlated with the frequency of anal receptive intercourse but not with anal douching. This finding contrasts with the unpublished data cited by the authors on the risk of anality.

Second, because the prevalence of specific sexual activities among men who studied clinically is not well documented, assigning relative risks to specific sexual practices is difficult. Thus, when Reiner and associates (1) cite an estimated 40% incidence of morbid complications from anal intercourse in gay men, they overstate the support of their references. Owen (3) does not offer any incidence figures, and the data of Kazal and coworkers (4) were drawn from a proctologic practice, certainly not a representative sample of gay men. Bolling's report (5) of a low complication rate from anal intercourse, although drawn from a heterosexual female population, suggests caution in attributing morbidity to anal intercourse itself. Two of us helped prepare a detailed questionnaire that included questions on sexual activities, history of sexually transmissible disorders, and number of partners; it was completed by about 600 people who approached the Bay Area Physicians for Human Rights booth at the Gay Community Day Parade in San Francisco in June 1981. These data are being analyzed and will be prepared for publication soon.

Third, mention is not made of the very common practice of using saliva (usually the insertive partner's) as a lubricant in anal intercourse. This factor is significant for two reasons: HBSAg-containing saliva can invade anorectal mucosal sites of injury or ulceration without anal douching, and saliva is a poor lubricant that probably permits anorectal mucosal injury more readily than when other lubricants are used.

Fourth, the presence of anorectal erosions in 13 of 22 patients (identical lesions in 12 of 13) of the author's sample seems high if the patients were selected only by the presence of hepatitis B antigenemia. The authors' conclusion that these lesions are "sexually induced" is unwaranteed by the data they present (if we are correct in assuming that they mean "traumatically"

REFERENCES


International Needs in Occupational Medicine

To the Editor: Since it was established in 1970 the National Institute for Occupational Safety and Health (NIOSH) has made a major contribution to the scientific and technical understanding of work-related hazards and health. Its findings, standards, and recommendations are used all over the world. Smaller countries with programs of occupational health and safety, protection, which cannot mount a full-scale scientific research effort of their own, rely on NIOSH studies and materials.

We call attention to the fact that reductions in NIOSH funding may have an impact well beyond the borders of the United States, a fact which may not be well understood by Americans. We do not believe that in doing so we are intervening in a domestic matter. Rather, we feel the obligation to inform those who may read this statement that the control, prevention, and reduction of occupational illnesses and accidents is an international issue to which NIOSH makes a major contribution. We respectfully request that this be brought to the attention of those who will determine the future level of NIOSH activities.

[Submitted by Victor W. Sidel, M.D. and Sumner M. Rosen, Ph.D.] on
The resolution before the Reference Committee today calls for significantly greater governmental funding and research into the cause and the development of an effective treatment program for the Acquired Immune Deficiency Syndrome.

One dramatic way of looking at the cost of an effective research program, which will, make no mistake about it, be very high, is to compare the cost of caring for patients with AIDS if the current epidemic continues on its present course. The first cases of what we now know as AIDS were diagnosed approximately three years ago. There are now over 2000 cases that have been reported to the Centers for Disease Control. If we can project the rate of rise in AIDS cases forward three years, which also represents the present upper estimate of the incubation period for this disease, there will be in excess of 50,000 AIDS patients in 1986. It has been estimated, by the Centers for Disease Control and others, that the average cost of caring for an AIDS patient ranges from $65,000 to $120,000. If we take $100,000 as a conservative average cost, we can see that the cost of caring for 50,000 patients will be $5 billion dollars.

This estimate for the cost of medical care for AIDS patients is based on today's prices. It does not take into account...
advances in treatment that may occur in the future. One possible treatment that has been proposed is interleukin 2. The current per patient cost of a course of interleukin 2 is a staggering $125,000. Although we might expect that this cost would come down with mass production, we can readily see how actual health care costs for treating AIDS might escalate in the future. I should also like to emphasize that the $5 billion cost by 1986 does not take into account any costs associated with research or prevention; it is the cost of patient care only.

As the number of cases continues to double, most AIDS patients are dying slow, usually respiratory, deaths. If the epidemic continues at its current pace, soon every ventilator in a city like San Francisco will be connected to a patient with AIDS. We will have finally reached the point where our health care resources have been taxed to their utmost. Then we as physicians will have to face the question of what to do when the next patient with chronic obstructive pulmonary disease and respiratory failure appears on our hospital’s doorstep or where to send the next Bayshore Freeway accident victim brought to our hospital’s emergency room.

What will the cost of research be for finding the cause of AIDS? As a solo physician engaged in the clinical practice of internal medicine, I do not pretend to have an answer to that question. But, to give you an idea of the magnitude of the costs we are talking about, I would like to tell you about a discussion
I recently had with Dr. Bruce Voeller, formerly a research biologist with Rockefeller University, and now the President of the Mariposa Foundation.

In order to isolate the putative AIDS agent, satisfy Koch's postulates and lay the groundwork for future preventive measures, such as a vaccine, an animal model will undoubtedly be required. So far, no one has been able to identify a primate or any other animal that is susceptible to the agent evidently causing AIDS in humans. The Centers for Disease Control note that it costs $100 per day to raise experimental animals. This high cost results from the fact that a number of special precautions will need to be taken for personnel working with the animals and the facilities housing the primates will often be contaminated and cannot be reused. In every laboratory, the traditional equipment used for research will not be adequate. For infection control reasons, special exhaust hoods, separate centrifuges and animal caging will be required.

AIDS appears to take between 7 and 36 months to surface in humans and there is no reason to believe this period is significantly shorter in primates so let us consider an incubation period of 24 months in animals. Suppose we would like to study a minimum of six species of primates, and will be looking at 25 animals per species. Now suppose we want to investigate four different portals of entry of an infectious agent, say, injecting the agent intraperitoneally, parenterally, orally and intrarectally. Now also suppose that we want to look
at several possible vehicles that have been proposed, say, semen, blood, urine, feces and saliva.

One can readily calculate that the total cost of such a study will be $219 million, and this is just to look for the proper experimental animal to use in further research. And we have not even considered the fact that we might require more refined studies, like dividing the blood into cellular and plasma fractions and injecting each of them; or, the fact that we might need to analyze our results in various ways, such as column chromatography, gel electrophoresis and ultracentrifugation. Although we might do these studies sequentially, we must remember that the incubation period of the agent is measured in terms of years. So the only real alternative is to do all of the studies simultaneously.

So far we have not even considered other areas of research that may be required. In addition to the experimental animal studies, there must be immunological studies, virological research leading toward a vaccine and investigation of possible surrogate markers of AIDS infection in the blood. There should be a program to look at prodromal traits of AIDS infection and to do longitudinal follow-up. This will require tissue and blood studies which will, in turn, necessitate freeze storage in a facility that must be developed, requiring storage of specimens at -70 C under liquid nitrogen, using sophisticated infection control precautions. Finally, a new case control study should be
organized by the Centers for Disease Control. Many physicians treating large numbers of gay patients realize that the case control study just published last month in the *Annals of Internal Medicine*, and in which I participated, was based on the very first patients who were identified as having AIDS. We need data that reflects the disease as it exists now.

The review process for research proposals also needs to be expedited. The National Institutes of Health and the Centers for Disease Control should be encouraged to call for research applications more frequently, perhaps every three months, rather than annually. Those proposals which have been peer-reviewed but not fully funded should be fully funded. A blue ribbon *ad hoc* committee must be convened by the Department of Health and Human Services to expedite review of these proposals to determine which research projects would be in the best interests of the public.

I think, ladies and gentlemen, that you can readily see that an adequate AIDS research program will be expensive. If the experimental animal study will cost $200 million as we have estimated, one can easily imagine that the additional necessary immunologic, virologic, serologic, clinical prodromal and clinical case control studies will bring the total funds necessary to determine the cause of AIDS and to follow the clinical course of the disease to well over $500 million.

In the current fiscal year, $14 million was appropriated for AIDS. This represented some funds shifted from other sources.
Congress has added $12 million in new monies. The Administration then diverted $14 million from other sources. So a total of $40 million will be spent on AIDS this year, only a fraction of the amount we see as being required. More importantly, we have not been told about any systematic, identifiable plan for AIDS research activities. It seems to me that we need to go about this program in the same coordinated way that was employed, for example, in America’s space program.

$500 million sounds like a lot of money. But it is an extremely small amount when compared to the risk of further contamination of the blood supply with the additional cases of AIDS that will ensue. It is an extremely small amount of money when compared to the patient care costs of $5 billion that I have projected for three years down the road.

Ladies and gentlemen, in this battle we are no longer counting time by hours, days or weeks. We are now counting time by the tens of people who die each week of this disease. Let us ensure that I will not be sitting before you next year talking about the hundreds of people who die each week of AIDS. I urge you, not only as an internist caring for AIDS patients, but also as a gay man, to support the resolution on the Acquired Immune Deficiency Syndrome, and to put the power of the American Society of Internal Medicine fully behind its implementation.
The Clinical Approach to the Male Homosexual Patient

William F. Owen, Jr., M.D.

Reprinted from

Medical Clinics of North America

Volume 70, Number 3, May 1986
William Owen, Jr., M.D.
Gay Health Care Since 1979
Board Certified  
Primary Care
HIV/AIDS Care  
Second Opinions
Early AM, Evening
and Same Day Appointments
415.861.2400
45 Castro St., Ste. 402 SF at Davies Medical Ctr.
conditions that, with a positive HTLV-III antibody test, could be included in the surveillance definition. I believe pulmonary tuberculosis was one of those. I'm not sure whether that was the first thing that they let in the door with a positive HTLV test. It wasn't a condition that could only occur in people with HIV disease.

AIDS as a Disease Spectrum

At some point, though, after HIV became described and known, it began to dawn slowly on us that the consequences of this infection were a spectrum all the way from asymptomatic, through what we were then calling AIDS-related complex or AIDS-related conditions, to AIDS with severe indicator diseases. Once we began to understand that spectrum, those of us who were clinicians began to steer away from the CDC's definition, because it wasn't clinically relevant for us any more. We understood that it was a spectrum, and that for epidemiological-- [pl. complete]

Hughes: I see, and they were way over--

Bolan: --on the sick end of the spectrum. The genesis of the term ARC was probably born out of an intention to broaden that case-finding net, but to make a different category, and to say, "We're going to group rather than lump, because we don't know whether we can lump
uncomfortable dealing with it; they feel threatened by that. But
I really keep up with the literature; I keep up with my
conferences. So if there is available knowledge, I certainly
should be able to provide it.

Keeping Informed about AIDS

Medical Journals

Hughes: How do you keep up with the AIDS literature, which is so vast?

Owen: Well, there are several ways. I subscribe, first of all, to a
number of journals. The most important ones, I guess, would
be the New England Journal of Medicine, the Annals of Internal
Medicine, Journal of the American Medical Association, the
Archives of Internal Medicine. Also we get a number of HIV
newsletters which give synopses of recent studies or that focus on
patient care issues.

The other resource I have are more obscure journals. I
asked the librarian at our medical center at Davies to produce a
regular—and she does this every week or so—synopsis of the
latest articles on HIV that have appeared in Medline, particularly
focusing on HIV and treatment. So I get a computerized printout
of that. If there are any articles that appear relevant, I can
ask her to request the copy from interlibrary loan if we don't
have the journal.
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Sally Smith Hughes

Graduated from the University of California, Berkeley, in 1963 with an A.B. degree in zoology, and from the University of California, San Francisco, in 1966 with an M.A. degree in anatomy. She received a Ph.D. degree in the history of science and medicine from the Royal Postgraduate Medical School, University of London, in 1972.


Presently Research Historian and Principal Editor on medical and scientific topics for the Regional Oral History Office, University of California, Berkeley. Author of The Virus: A History of the Concept, Sally Smith Hughes is currently interviewing and writing in the fields of AIDS and molecular biology/biotechnology.