FIGHTING A PLAGUE: DOCTORS' STORIES OF CHALLENGE AND INNOVATION
COMBATTING THE AIDS EPIDEMIC IN 1980’S NEW YORK CITY

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This senior thesis analyzes the early years of the American AIDS epidemic from the perspective of physicians working in New York City during the 1980’s. Now that the human immunodeficiency virus has devastated the United States for thirty-three years, it is increasingly important to analyze the early years of the epidemic to determine what the medical community has learned from AIDS. Much of the existing AIDS narrative has focused on either the biomedical research on HIV or the AIDS activism and health policy. Recent films depicting the fight against AIDS have displayed a polarity in the representations of AIDS physicians, which reflects the lack of scholarly work analyzing the physicians of the epidemic; those who saw the epidemic unfold in front of their eyes.

This study asks, how did physicians working in New York City respond to the beginnings of the AIDS Epidemic in the 1980’s, and how has this affected American medicine? To answer this question, the study analyzes theory, epidemiology, history, biology and primary research in the form of eight in-depth interviews of physicians who worked in New York City during the early AIDS epidemic. Their specialties ranged from neurology and nephrology to critical care and ophthalmology. Their ages, hometowns, sexual orientations, genders and political stances varied, which provide multiple perspectives toward the early epidemic in New York. In this thesis I argue that HIV/AIDS provided unique biomedical, social and political challenges to the physicians working in the city of New York during the 1980’s in ways that no other epidemic
has. The physicians adapted to meet these challenges using methods that have become commonplace in American medicine to this day.
DEDICATION

This thesis is dedicated to all the victims of the human immunodeficiency virus as well as those who have fought it politically and biomedically.
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I would like to thank all those who made this life changing study possible. This thesis would not have been possible without the eight amazing physicians I interviewed: Dr. Maria DeVita, Dr. Michael DeVita, Dr. Dennis Greenbaum, Dr. Craig Keyes, Dr. Sharon Kiely, Dr. Vincent Patalano II, Dr. Keith Sanders, and Dr. Peter Zeale. Their efforts both in the hospital and during the interviews are certainly worth acknowledgement. I would also like to thank Professor Seamon and Colva Weissenstein from the Georgetown Department of American Studies, my fabulous advisor Shiva Subbaraman from the LGBT Resource Center, and my TA Cara Dickason for their guidance and support. Finally, I would like to thank the following people for impacting my perspective on the AIDS epidemic: Professor Susan Lynskey from the Georgetown Department of Performing Arts, Professor Robert McRuer and D Gilson from The George Washington University, Professor Ramzi Fawaz from University of Wisconsin Madison, Sage Sarason, Andrew Walker, Marlene Cox, Taylor Rasmussen and the cast of Dear Harvey.
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INTRODUCTION

AIDS in the 1980’s & Today

On July 3, 1981, an article appeared in the *New York Times* reading, “Rare Cancer Seen in 41 Homosexuals.”¹ At that point, New York was filled with a sentiment of hope. The Vietnam War was over. More and more women were entering the work force. The gay community was gaining legitimacy with the growing successes of their Gay Liberation movement. No one foresaw the significance of what the article described, which is evident in the article’s placement on page A20. However, this illness, which would go on to be named Acquired Immune Deficiency Syndrome, would become extremely significant. Over the course of the 1980’s, the human immunodeficiency and the social response to the epidemic would change both New York City and the rest of the nation.

AIDS is a very special epidemic because it provided a variety of new challenges that the medical community was forced to confront. First, it was a very new type of virus that at first no one knew how to respond to. Second, this epidemic, unlike others previously, did not impact all of society equally. Transmission was due to behavior, and it hit groups already marginalized by American society at a point in history when there was a resurgence of conservatism, embodied in the “moral majority” and Reagan era politics. Gay men and injection drug users (IDU) were the first groups to get the disease early 1980’s. Each group had different relationships with the medical community at large, the politicians that drafting policy and, most directly, the doctors that were treating them. The various biological, social and political challenges as well as the innovations that arose in response to such challenges are definitely worthy of study. This study intentionally focuses on the first decade of the epidemic, a period when researchers and

physicians were still learning the fundamentals of the virus and there was no cure. It was during this period when challenge and innovation was most extreme.

This period is extremely significant because of the scale of the tangible devastation that the HIV & AIDS pandemic has and is still causing. This thesis is an academic analysis and attempts to look at the epidemic from an objective position to determine how it impacted the medical profession. However, the significance of the human side cannot be ignored. This study in no way attempts to objectify the victims of an illness that was not only terminal, but also heavily stigmatized. The gay community’s suffering, even decades after the height of the crisis, is still tender. In many sub-Saharan African nations, the devastation is still incurring. Such destruction is worthy of study so that we can in any way prevent the next epidemic from being so disastrous. You can’t put a price on a life, and this thesis is dedicated to the victims of this insidious and crippling virus.

The Centers of Disease Control and Prevention (CDC), the national institute of public health in the United States in charge of monitoring disease, injury and disability within the United States and the world, defines an epidemic as “an increase, often sudden, in the number of cases of a disease above what is normally expected in that population in that area.”² This is different from an outbreak, which is localized to a specific geographic location, and a pandemic, which is spread transnationally across national borders and continents and affecting a wide variety of people. Epidemics occur for a multitude of reasons, such as when there is a recent increase in the amount or virulence of an agent, exposing an agent to a population that previously was isolated from it, or the appearance of a new agent. HIV/AIDS was the latter, which explains the surprise and subsequent devastation in the United States. In the early years of the epidemic,

before there was effective treatment, AIDS deaths increased in number. 50,280 people died of AIDS from 1981-1987 and 202,520 died from 1988-1992.  

In this point in history, the year 2014, America is in the 33rd year of the AIDS epidemic. AIDS has now developed into a pandemic, with people infected with the human immunodeficiency virus on every continent. The epidemic has spread across the nation and the world to all races and socioeconomic levels and ARV therapy has extended the life expectancies of HIV positive patients to be essentially equal to those who are HIV negative. However, this was not always that way. The epidemic began with a trickle of gay patients coming into hospitals in 1981, dying of a wide variety of diseases that previously were uncommon and treatable in young patients. The first cases in the United States were localized to major metropolitan areas with sizeable gay populations, such as San Francisco and New York City. The cause of AIDS was determined to be a virus in 1983 and by 1987 researchers developed the first medication for the virus itself, AZT. However, the virus still had a high mortality rate until the development of multiple drug HAART therapy came out in 1995.

The early epidemic is also worth analyzing at this juncture because there is now emerging a sexually active generation who never knew HIV as an uncontrollable and lethal virus. This generation did not experience the pain of losing a friend, family member or lover or the fear of being infected by an incurable disease whose diagnosis was equated to a death sentence. Therefore, the emergence of this new generation has shifted the still ongoing epidemic. The incidence, or people newly infected with the virus, is disproportionately young. Though Americans age 13-24 make up only 17% of the population, they account for 26% of all HIV

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The greatest impact is in the gay community. In fact, young men who have sex with men (MSM) is the only demographic where new infections are currently increasing, with a 22% increase in recent years. Young MSM accounted for 72% of all new HIV positive diagnoses of youth aged 13-24 in 2010. Many of the physicians interviewed actually mentioned the trend of the epidemic becoming younger, which is interesting, because those numbers had been decreasing until recently. This new trend is due to decreased adherence to preventative measures such as condom use in this demographic. In addition, the epidemic is shifting to affect African Americans disproportionately to the rest of American society. With these shifts, it is important to talk about the early epidemic to teach younger generations who did not live through it. We must remain vigilant and learn from our history.

**Literature Review & Contribution**

Because of the medical, social and political value of examining societal response of the epidemic, there has been a great deal of scholarly research about it over the course of the decade up to today. Paula Treichler, within the chapter of her book entitled “AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification,” contributes to the discussion of AIDS. She theorizes on the impact of language surrounding the illness and how language, though humanly constructed, impacts our understandings of a natural phenomenon. AIDS was initially formally referred to as Gay Related Immune Deficiency (GRID) before it was given its current name, which forever marked the disease with a specific group. This, in turn, impacted social,

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7 Ibid.
biomedical and political response to the epidemic. Other theorists, such as Douglass Crimp, contributed to this dialogue. In his word “How to Have Promiscuity in an Epidemic,” Crimp asserts how AIDS era policy and gay culture prompted the gay community to mobilize to combat the epidemic.

As we begin to look back at the early AIDS epidemic, it has become increasingly important to monitor how the early epidemic is portrayed. The overall narrative of the early AIDS epidemic is constantly shifting with the rapid influx of scholarly work and mainstream media. This work has revealed a hole in the AIDS narrative. While the politics and the science of the epidemic is widely reported on, the narratives of the physicians – those who saw the epidemic play out in front of their eyes – has been absent. Such absence, in turn, has become clear in recent media portrayals of physicians in the epidemic, which have either demonized or sanctified the physicians who looked after AIDS patients. Critiques of medical workers at the time were often over exaggerated and not indicative of the actual challenges they faced at the time.

At this point, the early phase of the AIDS epidemic, before the current life-sustaining regimens were developed, is far enough in the past for it not to be a prominent part of collective memory. For this reason, in recent years there has been a resurgence of films depicting the AIDS epidemic. In the past three years, multiple films about AIDS have been released, such as the Oscar-nominated documentary How To Survive a Plague, which examines the AIDS Coalition To Unleash Power (ACT UP), United in Anger, which also examines ACT UP, and Dallas Buyers Club, which was nominated for six Oscars and provides a commentary on FDA drug approval during the epidemic. The films’ prominence was even a part of my own motivation to examine this period in greater depth. In some aspects, the resurgence of films is a good thing. It
captures the significance of a period that fundamentally changed many facets of the world. However, in other aspects, it is problematic because how the films capture the epidemic affects how people remember the epidemic.

A trend that is noticeable across the diverse films that have emerged depicting AIDS is the polarity of the representations of the physicians. In a sense, the films illuminate the gap in academic analysis on the epidemic. Most analysis focuses on the opposing political factions of the epidemic, either focusing on the policy-level response or AIDS activism, ignoring the individual narratives of the physicians themselves. The films tend to reflect the opposing factions, placing the physicians with the medical-industrial complex or on the side of the victims. In some films, such as *Angels in America* and to an extent *Dallas Buyers Club*, the physicians are completely demonized as cold, white heterosexual men who care only for money and prestige. In others, such as in *And the Band Played On*, the medical community is portrayed to be selfless defenders of their patients and a diverse community in race, gender and sexual orientation. The goal of this study is to fill the gap in academia and media representations. It is important to uncover the narratives of medical professionals working in New York City during the 1980’s to contribute their perspectives to the overall narrative of the AIDS epidemic.

Though there is plenty of existing scholarship on the role of the Reagan administration, Center of Disease Control, National Institute of Health and gay activism, there is relatively little scholarship on the role of medical professionals themselves. In large amounts of the scholarship, medical professionals working in New York City during the AIDS Epidemic were framed in

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10 *And the Band Played On*, directed by Roger Spottiswoode, screenplay by Randy Shilts and Arnold Schulman (Home Box Office, 1993), DVD.
between the crossfire of AIDS activists demanding visibility and access to healthcare and large
government agencies such as the Centers for Disease Control, National Institutes of Health,
Department of Health & Human Services and Reagan administration reacting to a growing
epidemic. I intend to fill in a missing part of the story of AIDS by examining the AIDS Epidemic
from the perspective of the medical professionals caring for AIDS victims themselves.

I plan on contributing to the limited studies previously done on the medical community
during the AIDS Era. Peggy McGarrahan’s Transcending AIDS: nurses and HIV patients in New
York City examines the interactions between nurses and HIV patients in New York City during
the early AIDS era. Because nurses have more patient contact than doctors do, the nurses formed
more personal relationships with HIV patients than other medical professionals such as doctors.
However, McGarrahan’s work only provides one part of the story. There are plenty of other
perspectives within the health sector that are equally important to discuss. By examining other
roles in the health sector, such as physicians of different specialties, I would expand on the
existing narrative of NYC hospitals during the early AIDS epidemic. I intend to paint a more
comprehensive picture of the struggles medical professionals faced in the early stages of the
epidemic, when so much was uncertain. The purpose of this research is to understand the
mindset of medical professionals working in New York City during the early years of the AIDS
Epidemic. My research question asks, “How did physicians working in New York City respond
to the beginnings of the AIDS Epidemic in the 1980’s, and how has this affected American
Medicine?”

**Methodology**

To answer the research question, I have turned to theory, epidemiology, history, biology
and primary research in the form of eight in-depth interviews of physicians who worked in New
York City during the AIDS epidemic. Their specialties ranged from neurology and nephrology to critical care and ophthalmology. Their ages, hometowns, sexual orientations, genders and political stances varied, which provided multiple perspectives toward the early epidemic in New York. This study will examine the individual narratives of different medical doctors who worked in New York City for varying amounts of time during the 1980’s to construct a generalized narrative of physicians fighting the early AIDS epidemic. Though each new interview adds a new layer of complexity to the narrative, the interviews are used as representatives of their colleagues working in the health sector of New York City at the time. The interview process took place over a series of a few months.

Because the subjects worked in New York City twenty-five years ago, recruitment was one of the largest challenges of the study. Each one of the medical doctors came from different backgrounds and had different specialties in medicine. They were recruited through reference and agreed to participate. Reliving the decade was hard for some. At points during various interviews it became hard for participants to recount the horrors that they had seen and the emotions they felt over the course of the epidemic, which was palpable in the tone of their voices and expressions on their faces. Some refused to even participate in the discussion because of the memories and issues it brought up. The sensitivity of the questions even came to the attention of the Georgetown Internal Review Board (IRB), which called for all sensitive questions about misogyny, classism and racism (but not homophobia) be stricken from the content of the interview. Some of the doctors participating sought to actively combat the epidemic, while others were faced with it based on their proximity to it while working in New York City. Because their background is important to understanding their perspectives, it is useful to introduce each of the
eight physicians who were interviewed as part of this study. These introductions can be found in Appendix II.

It is important to note that the sample was not blind or large. Though a large, random blind sampling would have been ideal, the study had very specific requirements for participation as a subject. The subjects were originally collected based on references stemming originally from my existing social networks, but eventually from the participants themselves. This may skew the nature of the data collected, though every effort was made to recruit the most diverse and representative sample as possible. Ideally the sample would be either blind or large enough to compensate for the skew, but time and resources were limited.

It is also important to mention some of the potential biases that may influence both the data and analysis of the study, though they were minimized as possible. First are my own biases as a white, gay-identified male cisgendered student with no personal experiences with intravenous drugs. A majority of my family members, all of which were raised Catholic, reside in the New York metropolitan area. I have an academic background in both science as a premed student and queer studies, which inform my analyses. In the data itself, three of the interviews were members of my own family. Though my family’s involvement in the epidemic was one of the factors that sparked my initial interest in the topic, my relation to them may have affected what information was shared with me even though I asked all subjects to be as honest as possible. Dr. Michael DeVita and Dr. Sharon Kiely, who were both completing their medical residencies at St. Vincent’s Hospital in Chelsea, Manhattan during the 1980’s, are my parents. In addition, Dr. Maria DeVita, who completed her residency at Lennox Hill Hospital during the epidemic, is my aunt and godmother.
During interviews, I have attempted to get into the mindset of the subjects during the 1980’s. There was a list of standard questions designed to examine some of the large and unique biological, social, and political challenges that the AIDS epidemic presented to the medical community working in New York City. However, each participant had a specialized experience so the questions varied to get the best understanding of their distinct perspective. Therefore the questions varied greatly, from conducting spinal taps while pregnant, retinal surgery and neurotropic affinities of HIV to neighborhood changes and political protest. In addition, I asked subjects to comment on the large critiques of the medical community during the era, such as inefficiency in drug approval and bias in the hospitals. The subjects were asked to reflect on very sensitive topics, such as death, homophobia, racism, sexism, classism and the limits of their profession. Though the subjects were prompted to speak from their experience as honestly as possible, the sensitivity of the subject matter could have impacted the answers.

In order to ensure the highest quality research and lack of bias, I followed the guidelines of Georgetown’s Institutional Review Board (IRB). I provided all of the interview subjects with consent forms and will respect subject privacy. The interviews were conducted in person if possible, but due to geographical location, most were either audio or video conversations using Skype or FaceTime. During the interviews, I audio record the subjects while taking notes using Microsoft Word so that a full transcript could be written for each (See Appendix III: Transcripts). Following the interview and as I begin to wrote the final paper, I contacted the subjects with any further questions to clarify their responses, as necessary. In addition, in order to ensure that I captured the subjects’ thoughts correctly, I sent all selected and truncated quotes to the subjects’ before finalizing them within the context of the paper. In this way misquoting or misinterpretation was controlled.
In addition to the interviews, I turned to various secondary sources. Many of these sources were previously explained in the literature review, such as the works of Douglas Crimp and Paula Treichler, who provided non-scientific perspectives on the AIDS epidemic and how it affected American society, as well as a similar study conducted by Peggy McGarrahan for her dissertation. McGarrahan examined nurses and AIDS patients in the early 1990’s in New York City. In addition to these texts, I examined a combination of sociological texts, documentaries and biological textbooks to better frame the epidemic and the physicians’ work in 1980’s New York.

**Thesis Statement**

As stated previously, no two narratives of the interviewed physicians were the same. In fact, it was striking how different each of the physicians were, which attests to how encompassing AIDS was in New York City at the time; it truly impacted every sub-specialty of physician in Manhattan. Nonetheless, there are some common threads connecting the narratives. In this thesis my primary argument is that, based on the interviews I have completed combined with secondary research on the AIDS epidemic, it is evident that HIV/AIDS provided new, unique biomedical, social and political challenges to the physicians working in the city of New York during the 1980’s in ways that no other epidemic has. The physicians, over the course of the 1980’s, adapted to meet these challenges using methods that have become commonplace in American medicine to this day.

**Overview**

The challenges that the physicians faced were many in number, but can easily be organized into three groups: biomedical, social and political. Thus, the chapters will be organized in this way, with each presenting different challenges and their solutions. The first chapter will
focus on the biomedical challenges of HIV & AIDS. For the physicians, this was often the most
difficult to wrap their heads around. HIV was a new type of disease in many ways, which will be
explained in length in Chapter 1. It had a unique method of replication and mechanism of
progression in the human body that eluded physicians for years. In addition, the virus attacked
the body in a unique way; targeting not somatic, or normal body cells, but instead the
lymphocytes, cells of the immune system itself. Such biomedical ambiguity caused debate
internally within the medical community about how to care for patients during the epidemic. The
physicians met these challenges by adapting in unique ways to care for the patients with the
limited information that they had. As new biomedical research was produced internationally,
they adapted again and again to increase the quality of care for patients. They created new
epidemiological procedures, such as national infection reporting, which continue in epidemics
today. In addition, they worked to improve the level of safety for all hospital workers by
implementing universal protection procedures that live on to this day.

The second chapter will move on to discuss the various social challenges that the AIDS
epidemic presented to the physicians. The largest social factor was the fact that the human
immunodeficiency virus did not permeate through all of society homogenously. Transmission
was and remains to be connected to various risk behaviors that affected some groups more than
others. It is interesting to note that the first victims of the disease, gay men and injection drug
users, both occupied the margins of society at the time. For this reason, many did not have the
same access to health care as other, more prominent members of New York and American
society at that time. Because of the groups’ lessened presence in medicine both as health
providers and patients before the epidemic, physicians were forced to face these challenges head
on during the AIDS epidemic as the marginalized groups’ presence in the hospital soared. The
physicians, with heightened exposure to groups most hit by the disease, were challenged by the unique needs of each community. For the first time, the physicians had to work with their patients to figure out proper prevention and treatment strategies for each marginalized groups. In addition, they had to figure out the appropriate questions to ask, even if they are on socially sensitive matters such as illegal drug use and private sexual practices, to be able to provide the most specialized and therefore effective care possible. Such socially savvy care remains an important part of medicine today.

The third chapter will discuss the political challenges that the physicians of New York City faced over the course of the AIDS epidemic. As the second chapter of the thesis will articulate in depth, the first groups hit during the AIDS epidemic were heavily marginalized, and even stigmatized, in 1980’s American society. With only these groups getting affected by a lethal disease at first, stringent political factions arose. Conservative and mainstream Americans, unaffected by a virus that only affected morally questionable people in specific liberal metropolitan areas of the country, were reluctant to devote significant resources to fight the epidemic at first. In contrast, the victims of the epidemic, with their friends dying around them and their life expectancy shortened, resorted to radical tactics and community organization. The medical professionals working in New York City hospitals, whether they sought it out or not (and most did not), were faced with the politics of the epidemic on various levels. In the hospital level, some faced conservative hospital protocols over what they could or could not prescribe. In addition, there were debates over whether or not to quarantine AIDS patients. On a larger scale, the physicians were forced to face the repercussions of city and nation-wide medical and political policy. Some faced gaps in resource allocation and worked to meet the need by going out into the community and working in outpatient clinics. Others faced political groups, such as the AIDS
Coalition To Unleash Power (ACT UP), which used radical tactics to protest existing medical and political practices in the wards themselves. Overall, the physicians adapted to the political challenges and worked to meet the unique needs of their patients.

As you read each chapter, I implore you to take on the perspectives of the physicians. The quotations that make up the backbone of this study are the real thoughts and experiences of people still alive and working today. They were neither demons nor saints as recent media portrays them to have been. Instead, they were human. They faced monumental biomedical, social and political challenges during the early AIDS epidemic in New York City that they remember to this day. As you read through their stories of challenge and innovation, struggle and progress, step into the shoes of the physicians and learn from their experiences.
First and foremost, physicians are responsible for tending to the biomedical needs of their patients. Over the course of the AIDS epidemic, physicians were certainly tested on their biomedical knowledge. HIV & AIDS was new type of disease that presented many biomedical challenges for the physicians, such as HIV’s unpredictable latency period, staffing, opportunistic infection treatment, and new types of medications. With limited knowledge and resources, the physicians created innovative solutions to the biomedical challenges. They improved epidemiological reporting, implemented AIDS wards, developed treatment to increase immune function and fight opportunistic diseases, reframed the epidemic for health workers and developed universal precautions to prevent transmission. Many of these developments are still important for American medicine today.

Biomedical Background of HIV/AIDS

Though this report is fundamentally a social and historical analysis, it is essential to elaborate on the biology the human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). The mechanism by with HIV penetrates the body and operates within the human body impacted social and medical responses during the early stages of the epidemic.

HIV is an acronym for the human immunodeficiency virus. As a virus, it is a combination of protein and genetic material that requires a host, such as a human cell, to reproduce itself.\textsuperscript{11} Viruses are considered parasites because they reproduce at the expense of host organisms.\textsuperscript{12} They are not organisms themselves because they cannot reproduce without a host. Typical viruses use

\textsuperscript{12} \textit{Ibid.}
somatic, or normal body cells, as hosts. The body responds with the immune system comprised of various leukocytes, or “white blood cells,” which all have various jobs.\textsuperscript{13} For example, one leukocyte, the helper T-cell or CD4 cell, produces antibodies, which are proteins that prevent viruses from binding to cells to infect them. Another leukocyte is the killer T-cell (CD8), which attacks the infected cell. Eventually the leukocytes stop the virus. However, HIV is not like many other viruses. HIV attacks the body not through infecting somatic, or normal body cells like other viruses. Instead, it infects the leukocytes themselves (See Appendix I, Figure I). As HIV continues to replicate, it attacks the immune system.

HIV is also distinct from other viruses because it is a \textit{retrovirus}.\textsuperscript{14} The mechanism by which retroviruses infect the body is distinct from other viral forms. Instead of just copying its genetic material, it translates it into DNA to be integrated into the host leukocyte.\textsuperscript{15} At this point, it can use the host cell’s infrastructure to replicate the DNA to make new human immunodeficiency viruses or wait in a latency period. This latency period made it very difficult for physicians to diagnose the virus before an effective test was available. Retroviruses were only discovered in human beings a few years before the epidemic, with the discovery of HTLV-I in 1980 by Robert Gallo, who was credited with isolating HIV (originally called HTLV-III) in 1982.\textsuperscript{16} The new form of virus left many questions for researchers to uncover in order to develop reliable tests and treatments.

Because the virus operates by attacking leukocytes, doctors monitor the blood of the HIV patient for the number of leukocytes, specifically the “helper” CD4 T-cell to track the progression of the virus in the body. The amount of viruses in a specific amount of blood, and

\textsuperscript{13} Marina Coleman, \textit{HIV & AIDS} (Johannesburg, SA: Jacana Media, 2009), 56-65.
\textsuperscript{14} Ibid.
\textsuperscript{15} Scott Freeman, \textit{Biological Science}, 4th ed. (Boston, MA: Benjamin Cummings, 2011), 684.
the CD4 count fluctuates in a predictable manner (See Appendix I, Figure 2). Though the progression of the virus is predictable, the timeline of this is different in each person. For example, when the virus infects someone, the body goes through a process of seroconversion. This is when the body begins creating antibodies, during which the person only experiences flu like symptoms. After seroconversion is a latency period, during which the virus slowly compromises the immune system without physical symptoms. Dr. Keith Sanders described seroconversion.

I specifically remember a young man who came in and his initial symptoms were that he had a sore throat. Why would you get admitted to the hospital for a sore throat? But it wasn’t just a sore throat. He had lab results really abnormal, serious immune system problems, and what is called a coagulable state. He was forming blood clots unnecessarily. So his coagulation system was affected and his immune system was affected, and the only normal symptom he had was a sore throat. Long story short, this was one of the seroconversion cases where he came in and his initial test results were negative for HIV and later on we figured out that he was positive and what we were seeing were the massive immune system effects of becoming seropositive.17

As Dr. Sanders mentioned, the symptoms of seroconversion are similar to the flu, which made it difficult to spot early on in the epidemic. The first test for HIV, which was developed four years into the epidemic in 1985, was designed to find the antibodies that the body produces and not the virus itself. This confused physicians because the period of seroconversion is different in every person. In addition, the period of AIDS development/latency period was different in each person. The uncertainty of seroconversion and the latency period made it difficult for physicians to diagnose as well as create a prognosis, which is the likely course of the disease for the patient. Again, though the purpose of this study is not biological, it is important to know the biology of HIV to truly grasp the nature of the epidemic. The biological nature of HIV impacted the way physicians responded to the epidemic.

17 Keith Sanders, interview by author, December 27, 2013.
**Disease Reporting**

One of the largest barriers was the simple fact that many of the physicians working in New York City and the rest of the nation had no experience operating within an epidemic. Most physicians had only studied American epidemics in history lessons. They were simply unprepared for what they were about to face. Dr. Sharon Kiely recounted the medical community’s mindset leading up to the epidemic.

Remember there wasn’t anything like this in anybody’s experience because all of the big epidemics like polio, measles and all of this stuff were behind us. Tuberculosis was gone. There were decades and decades of health.\(^\text{18}\)

Dr. Craig Keyes chose to enter into the epidemiology of HIV during his residency, which is the period or specialty training after medical school. He remembers being discouraged from the field by the chairman of medicine at Lennox Hill Hospital, which is located in the Upper East Side of Manhattan.

The one thing I will never forget has to do with medical education. I will never forget the chairman of medicine at Lennox Hill said to me after I finished my residency – they wanted me to come and run the AIDS unit at Lennox Hill Hospital. The Chairman of Medicine said ‘I think you’re going to really regret it at some point because AIDS is really popular right now and a gold mine for getting funding. And everybody else is getting cheated out of their funding. So it’s not going to be the focus forever. You’ve got to decide if you’re going to go with it and run that risk or expand and get a broader skill set.” I didn’t like that and reacted negatively to it. I was shocked that somebody in that position would even think that let alone express it.\(^\text{19}\)

Such sentiment expresses how epidemics were seen at this time. AIDS was seen as a medical scare that would pass instead of a disease that would be so prevalent for years to come. It is clear that the onset of AIDS caught most doctors completely off guard, with some not even seeing it as worthy of further study. This quotation reveals that some physicians at the time saw the epidemic in terms of funding and not treatment or care. With no experience with past epidemics and with a

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\(^\text{18}\) Sharon Kiely, interview by author, November 6, 2014.

\(^\text{19}\) Craig Keyes, interview by author, February 5, 2014.
general lack of value in epidemiological study, physicians were not prepared to respond the growing number of AIDS patients.

With an illness this complex and new, doctors faced a load of challenges because they were ignorant to the nature of the disease and how to handle epidemics. One of the largest challenges early on was with diagnosis. With so many young people dying from diseases previously seen only in elderly immune compromised patients, doctors were baffled. They had no idea what it was and how to diagnose it. Dr. DeVita remembers the difficulties around diagnosis with the first couple AIDS Patients come into the Intensive Care Unit (ICU) of St. Vincent’s Hospital in 1981, the first year of the epidemic.20

There weren’t a lot of people. There were just a couple. The first report was in 1980 with just seven patients. It was a really rare disease at that point. We didn’t know there were opportunistic infections. They had diarrhea that we couldn’t diagnose, then they had pneumonia that we couldn’t diagnose, then they had skin legions that turned out to be Kaposi’s Sarcoma that was so rare that people couldn’t believe it or the diagnosis wasn’t correct.21

With their inability to diagnose the illness, they referred to the help of the Center for Disease Control (CDC), a federal agency under the U.S. Department of Health & Human Services that tracks progression of diseases all over the world. Dr. Michael DeVita remembered his correspondence with the CDC with regard to one of his patients during the first year of the epidemic.

I do remember when I was in the ICU I had a patient with pneumocystis and I had to call the CDC to report it and the CDC flew a medicine to JFK [Airport] and I had to call for someone in the hospital to pick up the drug, which was called Pantamidine and bring it to the hospital. The patient died. It was that rare and that weird that we had to call the CDC to get the drug, which wasn’t released. We had it special on a compassionate use protocol. That told me that the government and CDC knew about it and had done enough

20 Note that at this point, AIDS was not named and the physicians can only identify their diagnosis as such retroactively.
21 Michael DeVita, interview by author, November 1, 2013.
investigation on it to know what the treatment should be. It was in 1981. I think I took care of 2 or 3 patients that year that had AIDS, though it wasn’t called that then.\textsuperscript{22}

This quotation reveals the disconnect between the CDC and the physicians working in American hospitals. Such reporting procedures were very rare in medicine. It was ambiguous what was reportable and what was not. Meanwhile, the CDC had more and more reports of an unknown disease and did not actively relay such information so the health workers could keep a look out. However, the AIDS epidemic would expand physician knowledge of epidemiological procedures, such as reporting.

The human immunodeficiency virus eluded physicians because a new epidemic was unexpected, and they were not prepared to face it. In some ways, the epidemic caused a renewed interest in the sub-specialty of epidemiology within the medical profession. Many of the physicians noted that this was one of the ways that the epidemic had a lasting impact on the medical community as a whole. Dr. Keith Sanders noted, “On a practical level, it led to the emergence of infectious disease doctors. You know, I think for a lot of them 10-20\% of their practice is just managing HIV.\textsuperscript{23}” Dr. Sharon Kiely agreed with this sentiment, describing how the tools learned from the AIDS epidemic translated into more recent epidemics, such as SARS. Kiely stated, “I think from better understanding of SARS, even West Nile, any of these viruses, now that we have a much more sophisticated response. [It is] more focused on the viruses than on the people.\textsuperscript{24}"

One of the largest parts of the new, sophisticated response was knowledge of abnormal medical cases to the appropriate entities, such as the Center for Disease Control. Though there were medical reports, as physicians such as Dr. Michael DeVita exemplified earlier in the study,\textsuperscript{22}

\textsuperscript{22} Michael DeVita, interview by author, November 1, 2013.
\textsuperscript{23} Keith Sanders, interview by author, December 27, 2013.
\textsuperscript{24} Sharon Kiely, interview by author, January 4, 2014.
standardized reporting was not in place. Dr. Sanders critiqued the earlier reporting, but asserted that it was not due to bias or other foul play, but on disorganization.

Each physician and each hospital across the country would not have a common means of sharing data. What each little silo was experiencing was not effectively collated until years later. There should have been a better epidemiological means of tracking that. So I would say that that is a valid criticism. Its not like anyone was purposefully doing something wrong, it’s just that there could have been a more concerted effort earlier on.\(^\text{25}\)

Dr. Kiely explained how the experience of working through the AIDS epidemic heightened general understanding about which cases are worthy or reporting or not.

There were reports. I think our ability to report has improved substantially. I think that people now know that if you see something odd in medicine, you report it. There is more understanding of what is reportable and what is not. Remember there wasn’t anything like this in anybody’s experience because all of the big epidemics like polio, measles and all of this stuff were behind us.\(^\text{26}\)

With more standardized reporting and heightened knowledge of when to report, the medical community has created a safety net for future outbreaks and epidemics.

**Safety Precautions**

Another set of challenges had to do with risk for the health providers, themselves. The physicians’ assessment of risk transformed over the course of the decade. At first, no one knew how the disease was transmitted, though they knew it almost certainly led to death. The fact that the epidemic manifested itself only in specific populations led some to hypothesize that the disease was sexually transmitted. However, there was a degree of uncertainty, physicians needed to implement procedures to minimize risk. The medical doctors initially used the highest amount of caution when treating AIDS patients. Dr. Dennis Greenbaum remembers the extent to which all the medical professionals interacting with AIDS patients.

\(^{25}\) Keith Sanders, interview by author, December 27, 2013.

\(^{26}\) Sharon Kiely, interview by author, November 6, 2014.
Well everybody was concerned about catching it because nobody had any idea of what was causing it...[W]e didn’t know what was causing it we used extraordinary precautions when we went to see a patient - this was the doctors, the nurses, and everybody. We wore total body gowns – everything was covered. We wore goggles, we wore masks, and we had covers over our heads, blue plastic full body garb, and gloves. That was the only way we went in to see those patients.27

However, such precautions were not limited to just the hospitals of New York. Dr. Greenbaum recalled how that carried on even in legal settings.

When these guys went to court, they were put in this booth to be separated from the jurors and everyone else. There was no way to keep everyone else isolated, so they put the suspected HIV patient into that booth.28

This quotation illustrates the extremity to which safety precautions were taken during the early AIDS epidemic in America. Uses of medical precautions like these were not limited to just patients of the AIDS epidemic. Dr. Michael DeVita attests that, ‘Gowns and gloves are no big thing in a hospital.’29 They are used in a wide variety of occasions in the hospital, commonly when working in the room of a patient with some form of communicable disease. When it became clear how the virus was transmitted from one person to another, the use of extensive gowning became less and less commonplace. It turned into an internal medical politics debate, which will be articulated in Chapter 3.

When it was determined that the disease was sexually transmitted virus, the physicians knew that AIDS was transmitted through bodily fluids. However, with no cure and no effective treatment for AIDS, physicians were very cognizant of the means by which they could contract AIDS while caring for patients and were extremely cautious in those scenarios. This made the physicians very cautious when dealing with bodily fluids. One of the largest

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27 Dennis Greenbaum, interview by author, December 18, 2013.
28 Dennis Greenbaum, interview by author, December 18, 2013.
29 Michael DeVita, interview by author, November 1, 2013.
fears of the medical workers was getting a needle stick. Dr. Keith Sanders remembered the fear as he entered the hospital.

In the early years when the virus was identified and there wasn’t an effective treatment there was a vast fear amongst house officers- that’s a common term for interns and residents - that’s who I was communicating with and those were my colleagues in those years – that if you got a needle stick, maybe you were going to die. There was that fear that you had a risk of getting HIV and you could die from it. We didn’t know that the risks were low.  

Almost all of the physicians interviewed shared the same sentiment of fear of needle sticks. There was no medication to prevent seroconversion, or transitioning to HIV+, after a needle stick as there are today. Dr. Kiely commented on this, saying “Now, when you get stuck with a needle you put people on prophylaxis. Back then we didn’t have that – you just didn’t have sex with your partner, not donate blood and basically sit and wait until maybe you got sick. It was very very scary.” In this quote, Dr. Kiely is referring to post exposure prophylaxis, which is an antiretroviral regimen developed in the mid 1990’s to prevents seroconversion from occurring after a possible HIV exposure. Many of the physicians commented on this fear with stories of extreme care when performing procedures and stories of sleepless nights.

To minimize risk of needle sticks and other forms of biohazard exposure, the physicians developed universal precautions. Dr. Keith Sanders remembers how the AIDS epidemic illuminated the risk medical professionals were taking at the time because they did not take the proper precautions.

In those years we weren’t using gloves all of the time. For example, now when you would draw blood you would never not wear gloves no matter what you did, no matter who the patient. In those days you would draw blood and sometimes you would get a little blood on your hands. The gloves were restraining and constricting, making it harder to find veins.  

30 Keith Sanders, interview by author, December 27, 2013.  
31 Sharon Kiely, interview by author, November 6, 2014.  
32 Marina Coleman, HIV & AIDS (Johannesburg, SA: Jacana Media, 2009), 66-70.  
33 Keith Sanders, interview by author, December 27, 2013.
Thus, physicians began to take very seriously the practice of universal precautions, such as washing your hands before and after treating every patient as well as wearing gloves. The idea is to treat each patient as if they had an infectious agent.

[AIDS] gave us a blueprint for universal precautions. The whole idea in health care is that you don’t just ask about the disease if you’re gay or use injection drugs, but you treat everyone as if they potentially have it. That all blood is potentially hazardous and those sorts of things. I just think we learned a lot.34

The implementation of universal precautions allows physicians to treat patients more objectively, rather than jumping to conclusions based on their identities. Moreover, it protected physicians from the myriad of potential illnesses that go through a hospital.

**Patient Volume**

A large biomedical challenge was the volume of patients with AIDS complications who needed care. As retroviruses were only recently seen in human beings, physicians were left with no drugs to prevent the progression of HIV in the body. The numbers of people coming to New York City hospitals with AIDS complications swelled and hospitals were filling up. With no medications to treat the patients sick from AIDS, the prognosis was very grim once someone was diagnosed with HIV or AIDS. Dr. Greenbaum remembers the early prognosis.

Once somebody had the diagnosis of whatever they called it then – Gay Related Immune Deficiency, GRID (And there were other names before it became HIV) – that patients with those conditions had 94-96% mortality…. So we could treat them for that, but we couldn’t do anything to the immune deficiency. Even with that particular treatment, most of the patients didn’t even survive their first episode of pneumocystis. Even with the treatment directly at the Opportunistic Infections, more than 94% died in the first treatment.35

As numbers of people dying from AIDS complications mounted, which was very taxing emotionally and physically on the doctors.

34 Sharon Kiely, interview by author, January 4, 2014.
35 Dennis Greenbaum, interview by author, December 18, 2013.
Over the course of the decade, many of the hospitals in New York City handled the influx of AIDS patients by constructing wards of the hospital devoted specifically for AIDS patients. Such separation and isolation of patients who have been exposed to an infectious agent, in this case HIV, is known as quarantine. Dr. Michael DeVita considered the motivations for quarantine to be altruistic, attributing the shift to the biomedical discovery that the disease could be transmitted via bodily fluids. The hospitals took on the quarantine model of previous epidemics throughout history.

They were definitely quarantining AIDS patients. Once we knew it was transmissible via blood and secretions, they were careful about putting patients in isolation. That is very common in medicine though – it goes back to year zero. AIDS patients were kept in a separate room.\(^{36}\)

However, not all of the physicians believed that the quarantine procedures were designed simply based on epidemiological precedent. As hospitals were filling up and the epidemic gained more media coverage, fear of contracting the disease grew. Patients in New York City hospitals at the time were nervous that they were going to contract the fatal disease while they were in the hospital. Dr. Peter Zeale remembers one of his patients expressing such fear about his roommate.

I knew there were concerns if the patient was in the same room as an HIV patient. Somebody came in – somebody with pneumonia – and he did not have HIV. His roommate came in that night and he began asking, “you know that guys coughing. Am I going to get it?” And you knew the guy had HIV. At that time, they weren’t quarantining anybody and there were a fair number of patients who were mixed in together. It was kind of difficult because you wanted to protect the privacy of the HIV patient and you would say to the other patient, well he has pneumonia and we’re treating him.\(^{37}\)

Dr. Craig Keyes proposes an alternative reasoning for the creation of AIDS units. He asserts that the hospitals constructed the AIDS wards because of the fear of other patients.

\(^{36}\) Michael DeVita, interview by author, November 1, 2013.
\(^{37}\) Peter Zeale, interview by author, January 11, 2014.
Well what I experienced was that there was an AIDS floor at Lennox Hill. The argument publicly was that all the special needs could be served. Effectively all of the experts were on the same floor. All the support services and the infrastructure was all on one floor. Many of us knew at the same time that that sort of quarantining or isolation was also for the benefit of the public relations department that didn’t wasn’t to have to deal with all of these movie stars at Lennox Hill having to be on the same floor or the room next door to somebody with AIDS. Those people just didn’t want the ventilation risk – coming up through the heater or the walls or something.  

In retrospect, the AIDS wards probably served both functions: to provide specialized care for patients suffering from AIDS while quelling the perceived risk of patients who feared contracting the fatal disease. Nonetheless, medical professionals adapted to the challenge of AIDS patient numbers through development of specialized AIDS wards.

**Medical Staffing**

Another issue was that of recruitment of medical professionals. During the early stages of the epidemic, information about the virus and how it is transmitted was limited. People just knew that it was fatal, which caused a widespread fear and stigmatization of AIDS. As certain facts about the epidemic arose, people reacted. For example, when people heard it was blood borne, there was a fear that it could be transmitted via mosquitoes. Dr. Kiely remembered her own fear of contracting the virus.

When my daughter was being born, there was this big rumor going around that if a mosquito was going around that had just bit a person with HIV and bit you, it could transmit. So people were closing their windows and looking for ultra thin screen and using bug sprays because there was this horrible rumor going around. Then there was me who was living there as a new mother, and I began to question if I was putting her at risk in any way.  

With such fear widespread and knowledge of HIV, people questioned coming into the West Village, which not only affected the local economy of the gay neighborhood, but also the number of people who wanted to be a hospital worker in those areas. Dr. Dennis Greenbaum

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38 Craig Keyes, interview by author, February 5, 2014.
39 Sharon Kiely, interview by author, November 6, 2014.
remembered a very drastic trend in residency applications at St. Vincent’s during the early years of the epidemic as well as the impact of AIDS on Greenwich Village, which was the gay neighborhood of NYC as well as the location of St. Vincent’s Hospital.

Our residents weren’t applying to St. Vincent’s because they were afraid to come [to Greenwich Village] because they were afraid they would die. Visitors wouldn’t show up. Patients with other conditions would elect to go to other hospitals.40

Doctor Sharon Kiely, who graduated from Georgetown School of Medicine in 1984, shared this sentiment of decreased demand to be in Greenwich Village, saying, “There weren’t a lot of people in my medical school class that wanted to train at St. Vincent’s in NYC.”

The lack of demand to care for AIDS patients was addressed on multiple levels, from incentive policy to moral imperatives. However, the physicians also worked to increase demand to care for the AIDS patients through reframing the epidemic. A frame, as defined by sociologist Erving Goffman, is “an interpretive schemata that simplifies and condenses the ‘world out there’ by selectively punctuating and encoding objects, situations, events, experiences and sequences of action within one’s present or past environment.” The medical professionals shifted the frame from that of risking your life to make a seemingly futile effort to lengthen the lives of gay men and drug abusers to a learning experience in modern medicine. Dr. Dennis Greenbaum described such efforts by the chairman of medicine at St. Vincent’s.

We had a new chairman of medicine that we knew kind of turned around the concept of having all these HIV patients by publicizing the fact that we had a very special disease here. He twisted the situation to make it more favorable to have people who were interested in infectious disease, that patient population, or the concept of finding with a brand new disease and working with those patients. So the number of applicants for the residency program was restored, came back up, and returned to its usual high level.42

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40 Dennis Greenbaum, interview by author, December 18, 2013.
42 Dennis Greenbaum, interview by author, December 18, 2013.
These innovative marketing techniques, as well as policy that will be explained later in the study, ensured that there were sufficient staff to care for the needs of AIDS patients.

**Opportunistic infections**

When a person is low on leukocytes in the body, such as during AIDS, there is ample opportunity for a slough of illnesses called “opportunistic infections” to infect the body. When a person has a low enough leukocyte count to contract opportunistic infections, they are said to have acquired immune deficiency syndrome, or AIDS.\(^{43}\) The World Health Organization, as of 2010, defines AIDS as when a person has a CD4 count less that 350.\(^{44}\) Because patients with AIDS are so suppressed immunologically, opportunistic infections are most often to be the eventual cause of death.

Opportunistic infections vary in structure. Some of the common opportunistic infections during the early years were the bacteria cryptosporidium and the fungus pneumocystis pneumonia. Cryptosporidium causes intense diarrhea, which causes patients to waste away through dehydration.\(^{45}\) Pneumocystis pneumonia impacts the lungs, making it difficult to breathe. Clearly, the opportunistic infections patients faced were extremely unpleasant. However, the opportunistic infections were not limited to infections. With the immune system so low, certain malignancies, or cancerous growths, develop. Dr. Dennis Greenbaum distinguished between opportunistic infections malignancies.

I shouldn’t say its just opportunistic infections, instead opportunistic events because the malignancies are not infections, so the immune deficiency resulted in a high level of certain malignancies as well as infections. And they were going to continue to go on until we were able to figure out the best way to manage the immune deficiency.\(^{46}\)


\(^{44}\) Ibid.

\(^{45}\) Michael DeVita, interview by author, November 1, 2013.

\(^{46}\) Dennis Greenbaum, interview by author, December 18, 2013.
One of the most common malignancies the early AIDS patients developed Kaposi’s Sarcoma, which is a type of skin cancer that manifests in purple tumors on the skin that typically appears in elderly men.

With the numbers of AIDS deaths grew and grew exponentially, researchers around the world began researching the way the virus operated in the body, looking for ways to stop it in its tracks. Meanwhile, with no medications to fight the virus itself, the physicians took it upon themselves to develop new strategies to boost the immune system and fight the opportunistic infections themselves. Dr. Maria DeVita commented on her own work to fortify the body of 75% of AIDS patients through monitoring body fluids and caring for renal (kidney) failure caused by immune-boosting medication.

Most of the people with AIDS in the 1980’s would have renal failure, usually from the Bactrim because the Bactrim can be nephrotoxic. They could have either high sodium levels or low sodium levels because of all the diarrhea they’re having from their cryptosporidiosis, and also potassium perturbations. The typical consult would be for some sort of electrolyte abnormality, and then dehydration. We just helped by guiding the fluids.\(^\text{47}\)

Dr. Greenbaum commented on the response in the Intensive Care Unit (ICU) to pneumocystis pneumonia, which was one of the most prevalent opportunistic infections during the early stages of the epidemic.

There were a lot of findings that also improved the outcome of the disease without affecting the retrovirus itself. For example, better treatment for pneumocystis a change in the delivery the type of illness that patients were presented to the ICU with. So that we saw a difference in what the patients had. We also saw that people weren’t dying anymore of pneumocystis when we had a little control of the immune system but better control of pneumocystis, especially when we knew there were other medications that could be added to the treatment such as steroids, which could make the patient better. So toward the end of the 1980s that the presenting manifestation of HIV was no longer pneumocystis. We began to see cardiac abnormalities – cardiac failure and other

\(^{47}\) Maria DeVita, interview by author, January 25, 2014.
conditions that needed to be treated with truly experimental therapy and all of these had there periods of hope and success.48

Strengthening the immune system through methods such as monitoring bodily fluids and using steroids as well as developing sound procedures for fighting opportunistic infections did lengthen the lives of AIDS patients. As new opportunistic infections emerged, the physicians worked to improve treatment. However, such care was only a temporary extension of life, for it did not fight the agent of AIDS, the retrovirus HIV.

Though opportunistic infections resulting from depressed immune function are commonly seen as the main damage of the virus, HIV also is harmful in itself. Dr. Keith Sanders remembers how the virus also operates to compromise the nervous system within the body.

The genetics of the HIV virus is the origin of its complexity. That’s why it’s been impossible to find an effective vaccine because the virus’ genetic makeup is so tricky and changes so frequently. The vaccine has been the elusive thing for 20 years now. The nervous system is susceptible to the virus itself. There are two aspects of the disease: the virus itself and the way the virus devastates the immune system. It allows the opportunistic infection. So the virus itself will invade and can cause damage to the brain and the spinal chord. If left unchecked – and it probably proportional to the viral load – it can creep in beyond the [blood] brain barrier and affect the nervous tissue itself.49

The blood-brain barrier separates the circulatory system of blood vessels from the brain. It is a selective barrier, only allowing specific nutrients in and keeping invaders out. Thus, the neurotropic nature of the human immunodeficiency virus can have significant effects on the body.

In 1987, medical response to HIV changed forever with the debut of azidothymidine, better known as AZT. This drug was part of a new breed of drugs called antiretrovirals, of which AZT was the first to be approved by the Food and Drug Administration. Antiretrovirals were not the cure for HIV, but they did slow down the progression of the virus in the body. They impeded

48 Dennis Greenbaum, interview by author, December 18, 2013.
49 Keith Sanders, interview by author, December 27, 2013.
the virus’ ability to replicate in the body, which kept the viral load down and made the body less likely to pass the virus on to others and contract opportunistic infections. The doctors all discussed the joy and satisfaction they felt with the advent of antiretroviral medications like AZT. Dr. Maria DeVita put into context what their discovery meant for those who cared for HIV/AIDS.

Oh my God, it was like a miracle. All of a sudden you would give people a pill and they would live. It was really amazing. I can imagine when they found the cure for polio or TB – It really changed everything. I had never been in something as dramatic as that. It was like when penicillin was invented. It was amazing.50

AZT was definitely an improvement, because for one the physicians had tools to fight the virus itself. However, initial dosage of AZT too high and maximized the side effects in patients.51 Moreover, after a certain amount of time, the virus would become resistant to the medication and proliferate again.52

Although this is not part of the period being examined, it is important to know that eventually successful HIV treatment arose that changed the epidemic. In 1996, researchers developed HAART, which stands for Highly Active Anti Retroviral Therapy.53 This therapy was a combination of three different types of antiretroviral medications. Dr. Dennis Greenbaum remembered the impact of HAART therapy.

They developed a system known as the HAART, Highly Active Anti Retroviral Therapy, that is so successful that now the longevity of a patient with HIV so long as the patient takes all of the standard precautions and continues their regimen as prescribed, the longevity is about the same as people without HIV.54

HAART changed the nature of the epidemic forever. No longer was an HIV positive diagnosis a death sentence. In addition, research to develop antiretroviral therapy like HAART heightened

50 Maria DeVita, interview by author, January 25, 2014.
51 Sharon Kiely, interview by author, November 6, 2014.
52 Dennis Greenbaum, interview by author, December 18, 2013.
53 Ibid.
54 Ibid.
the general scientific knowledge of genetics, the study of nucleic acids like Deoxyribonucleic acid (DNA) and ribonucleic acid (RNA). Kiely noted, “It opened up this whole world of molecular – and really genetic – medicine; the molecular or genetic basis of a disease.” In this way, AIDS research altered all of biology.

Medical Education

Although the physicians can be applauded for adapting to the vast array of biomedical challenges that the AIDS epidemic presented, the medical field can also be critiqued for its slow adaptation in the medical schools themselves. None of the five doctors interviewed who attended medical school over the course of 1980’s could remember HIV or AIDS even being mentioned within the classroom. Dr. Vincent Patalano attributes this to the early planning and slow response of medical school curricula:

I just don’t remember it, and I remember medical school well. Its not like it was a long time ago. I graduated in 1988. But I can’t remember them mentioning it. They probably mentioned it because it was already in the news, so how could you not. I don’t remember it though. I think its because the curriculum in medical school is not very responsive a lot to most current trends. They probably write the curriculum 3 years earlier, so I don’t remember them mentioning anything at that time.

Two of the physicians, Dr. Keith Sanders and Dr. Maria DeVita, remembered learning about AIDS not during the sit down classes of medical school, which occur during the first two years, but during the clinical years, which are the last two years of medical school. Dr. Sanders, who graduated in 1988, commented, “I don’t think I learned about it in detail until the third or the fourth year of medical school out in the wards and it was very primitive what we knew that, that is compared to what we know now.” Dr. Maria DeVita didn’t learn about the virus as AIDS, but as HTLV-III during her clinical years.

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55 Sharon Kiely, interview by author, January 4, 2014.
56 Vincent Patalano, interview by author, January 22, 2014.
I definitely did not have any formal lectures on it. There weren’t many discussions; we just went on it in rounds… By the time I’m first hearing about this was six months before I graduate, around early 1984. It was just the ICU rotation where they’re talking about HTLV-III.\textsuperscript{57}

With such slow response to the epidemic in medical school, new physicians were left to learn on their feet.

The AIDS epidemic posed multiple biomedical challenges for the physicians that affected how they treated patients, such as HIV’s retroviral structure, unpredictable latency period, safety precautions, a lessened work force, and an initial lack of treatment options. As more and more information came out, the physicians adapted new methods to respond to these challenges, such as implementing AIDS wards, developing treatment to increase immune function and fight opportunistic diseases, and creation of universal precautions to prevent transmission. Many of these developments are still important for American medicine today. However, the physicians were not only faced with biomedical challenges. The AIDS epidemic in 1980’s New York certainly presented a great deal of social challenges, which will be discussed in the following chapter. The social aspect of fighting the epidemic complicated the biomedical challenges and shaped American medicine even more.

\textsuperscript{57} Maria DeVita, interview by author, January 25, 2014.
CHAPTER 2
STIGMA & BIAS: SOCIAL CHALLENGES

AIDS presented a great deal of social challenges for the physicians working in New York City during the 1980’s. This is largely due to the types of groups that contracted the disease and the stigma associated with the disease. This epidemic, unlike others previously, did not impact all of society equally. Transmission was due to behavior, and it infected groups already marginalized by American society at a point in history when there was a resurgence of conservatism, embodied in the “moral majority” and Reagan era politics. Gay men and injection drug users (IDU) were the first groups to be subjected to the horrors of the human immunodeficiency virus during the early 1980’s. Each group had different relationships with both the medical community at large, the politicians that drafted policy concerning them and, most directly, the doctors that were treating them. Retrospectively, it is biomedically clear why these groups were where the epidemic spread first; Needle sharing during injection drug use and anal intercourse is much more likely to spread HIV than penile-vaginal sex. However, this information was not known at the time, which impacted how the prevalence of the epidemic in these groups was perceived.

AIDS Stigma

Stigma was one of the largest social challenges of the disease. Stigma, in this sense, is defined as “a mark of disgrace associated with a particular circumstance.” Stigma can have very negative effects on an epidemic, such as leading people to not get tested, not seek treatment or not tell anyone, which can assist in its spread. In one sense, many of the groups that were

60 Marina Coleman, HIV & AIDS (Johannesburg, SA: Jacana Media, 2009), 11.
first infected by the disease were already highly stigmatized. At that point, many men who had sex with men (MSM) either did not openly identify as gay or were “closeted,” because such sexuality was not as widely accepted back then. Dr. Keith Sanders commented on this sentiment.

Again, there wasn’t a lot of openness about homosexuality or sexually acquired infections in those days. I remember there would be men and their partners at the hospital. They would keep their cards pretty close to their chests. There wasn’t a lot of sharing of information. They were there because their partner was there and they were concerned and trying to help.61

Dr. Maria DeVita noticed this phenomenon amongst her coworkers at Lennox Hill Hospital.

There were a few guys that were actually very closeted, like even three guys that I worked with got AIDS and died…They were gay, but they weren’t openly gay…so I was like “oh my god I didn’t even know he was gay.” And then all of a sudden he had AIDS and died.62

In turn, other groups such as sex workers and intravenous drug users were formally stigmatized through the legal system. Therefore, it was extremely difficult to reach out to these groups, other than those working in medicine, to educate them on preventative measures.

Doctors attempted to solve this challenge through outreach. Physicians like Dr. Joyce Wallace, a primary care internist who worked in Greenwich Village during the 1970’s and 80’s.

Dr. Michael DeVita recalled her community engagement, reaching out to sex workers.

She figured out early on that the disease was likely spread via blood or other body fluids and started collecting blood samples from prostitutes in the area. She figured that at some point, even though this was an undefined gay disease, if it was communicated through blood, that it would contaminate needles and cross into the heterosexual population. She thought that prostitutes might become an important vector for transmission. She collected the specimens, and the NIH became interested and gave her a grant to continue this work. Basically, she paid the prostitutes for their time, and then drew blood during that time. It went to NIH where it was frozen until testing became possible, and then it was all studied. She also received a grant from a condom manufacturer and distributed condoms to help promote safe sex.63

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61 Keith Sanders, interview by author, December 27, 2013.
63 Michael DeVita, interview by author, November 1, 2013.
Some physicians also tackled the challenges that stigma presented through anonymity. Dr. Craig Keyes remembered NYC sanitation workers coming into his outpatient clinic because they knew that their names would not be taken down.

The most interesting one to me was just the whole challenge that many of the IV users had with disclosing to their sex partners that they had HIV or how they would protect their sex partners. It made sense because then if you were gay of course you had HIV; what’s to be embarrassed about? For IV users, they had to disclose that either they were having sex with men and they had to tell their wife that or they were using drugs, because those were the only possibilities then. It was very hard for them to keep their secrets. We had to learn to spend a lot more time on that than you usually would. There was much more of a mental health emphasis with the IV drug users than when you were with a gay guy.64

Stigma presented a very large social barrier to caring for HIV at the time. In fact, it is still one of the largest challenges of the epidemic to this day. The physicians working in NYC in the 1980’s attempted to tackle this challenge through community outreach and anonymous services.

On top of the stigma around the marginalized groups, there was stigma around the disease itself. The stigma was so strong it even impacted how certain neighborhoods were perceived during the epidemic. As mentioned previously, Dr. Kiely remembered a rumor that the disease could be transmitted via mosquitoes. The sense of fear around the disease caused the West Village, as New York’s gay neighborhood at the time, to experience a ghettoization over the course of the epidemic. Dr. Dennis Greenbaum mentioned this shift, saying, “The restaurants in Greenwich Village were all closing. Nobody wanted to go to the village to have dinner. There were all kinds of ridiculous concepts and fears that were all based on the fact that nobody knew what it was.”65 Such fear not only deterred New Yorkers from entering Greenwich Village, but also made members of the community leave. Dr. Craig Keyes noticed the vivid transition of the gay community, saying, “Nobody wanted to be in the West Village anymore. I think that’s why

64 Craig Keyes, interview by author, February 5, 2014.
65 Dennis Greenbaum, interview by author, December 18, 2013.
Chelsea was born. It was just too painful, too unpleasant. All of the places for casual sex just all closed or moved up to Chelsea. Everything changed.\textsuperscript{66} Such stigma surrounding a geographical location made it very hard for businesses in the area, such as Dr. Peter Zeale’s new private practice, which opened in 1983. He had difficulty finding and retaining clients in the area because he chose not to specialize in the care of an HIV/AIDS patient. The stigma surrounding the disease, and by association neighborhoods definitely challenged the medical professionals.

Physicians also noticed their colleagues stigmatizing those with AIDS, especially as they travelled outside of New York City. Dr. Vincent Patalano, after he finished his residency at Manhattan Ear & Throat in Manhattan, moved on to start his own private practice outside of Boston, Massachusetts. There, he witnessed the effects of stigma within the medical community.

I remember very clearly there was another ophthalmologist across the hall from me in a practice independent of me and I remember seeing a patient who came to me in around 1992 and he said to me that he had already seen another ophthalmologist 3 days ago and he basically told me everything was fine and shuffled me out. I saw this patient and saw that he had florid CMV retinitis, but I realized when I asked to see the other doctors notes just to see what changed that he hadn’t even done the most basic things we do in the exam: dilate the patient and look at the retina. I suspect this was because he knew that the patient had AIDS and he was terrified of catching it himself and the easiest thing to do was to get him out of the office.\textsuperscript{67}

Most physicians who worked in NYC during the epidemic did not experience such neglect first-hand, though such treatment was a main complaint of New York City based AIDS activist groups, such as the AIDS Coalition to Unleash Power (ACT UP). Multiple doctors expressed such treatment as they moved out of NYC, though.

Such stigma is not limited to patient-doctor dynamics, however. Michael DeVita even faced internal stigmatization as he moved from St. Vincent’s Hospital in the West Village to the

\textsuperscript{66} Craig Keyes, interview by author, February 5, 2014.  
\textsuperscript{67} Vincent Patalano, interview by author, January 22, 2014.
University of Pittsburgh Medical Center (UPMC) in Pittsburgh, Pennsylvania. Apparently, UPMC attempted to require him to take an HIV test as a condition of employment.

There was quite a scare. When I tried to move to Pittsburgh in 1988 they tried to not hire me unless I got an AIDS test. I fought it. I said that’s illegal. They said that they would hire me but wouldn’t insure me against AIDS. I said it’s fine by me because I didn’t know I had aids. I fought it all the way to the top and actually got the university to change their policy. They told me they were doing the test for employee records, but that they weren’t going to deny me a job for aids. I said I don’t care, it’s illegal for them to require an HIV test as a basis for employment.

This quote reveals that even employers of medical workers discriminated against people who had HIV. Though not all doctors faced such structural stigmatization towards the disease, the stigma surrounding AIDS was highly prevalent in American society at the time.

Physicians responded to AIDS stigma by being extremely cautious about patient confidentiality. An HIV positive diagnosis was such a burden that many people did not even seek to get tested out of fear of others finding out. For this reason, information regarding serostatus was kept in extreme secrecy. Dr. Sharon Kiely noted how patient doctor confidentiality was unique with AIDS diagnoses.

Early in the epidemic, confidentiality around the diagnosis was important because of the stigma to the individual and the fear about the potential for transmission to others… I think doctors have learned to be cautious that medical record information is sacred between the doctor and the patient. We have learned that insurance companies and employers could use it against the patient. So I would say that doctors were doing things to protect patients’ privacy before the laws changed.

In this quotation, Kiely mentions that stigma around the disease drove physicians to treat AIDS diagnoses with extreme discretion. Legislation takes time, and it took years for there to be laws protecting the rights of those with HIV. Dr. Kiely described how these laws codified what the physicians were already doing.

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69 Sharon Kiely, interview by author, January 4, 2014.
Over time confidentiality regarding the diagnosis [gained] special status in medical records and permission to share this information requires permission apart from general permissions similar to psychiatric and drug and alcohol abuse medical history.\textsuperscript{70}

In this way, patients could feel comfortable getting tested for HIV without worrying about other people, even other physicians apart from their doctor, finding out.

\textbf{Challenges Associated with the Gay Community}

When the AIDS epidemic is mentioned, even today, it is often attributed to the gay male community. This is because the early epidemics in both New York City and San Francisco, dubbed the epicenters of the epidemic in the United States, were most prevalent in the gay male population. The prevalence continues today, as 63\% of all new HIV positive diagnoses can be attributed to men who have sex with men (MSM).\textsuperscript{71}

During the early stages of the epidemic, one of the largest challenges was nomenclature. With different getting different opportunistic infections, doctors used trends in patient populations and symptoms to diagnose. Discourse around medical nomenclature is central to understanding the early AIDS epidemic in the United States. Paula Treichler contends within the first chapter of her book \textit{How to Have Theory in an Epidemic}, entitled “AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification,” that the medical community may not have been so scientific as they began AIDS research and named the illness. She says,

Our social constructions of AIDS (in terms of global devastation, the threat to civil rights, the emblem of sex and death, the “gay plague,” the postmodern condition, whatever) are based not on objective, scientifically determines “reality” but on what

\textsuperscript{70} Sharon Kiely, interview by author, January 4, 2014.
we are told about this reality: that is, on prior social constructions produced within the discourses of biomedical science.\textsuperscript{72}

In this way, she argues that the medical professionals subconsciously examined the retrovirus through socially learned biases. Such bias is most evident in the homophobic discourse prevalent amongst the medical community. Treichler tracks the nomenclature of the illness, from Wrath of God Syndrome to Gay Related Immune Deficiency (GRID) and finally to the current acquired immune deficiency syndrome (AIDS).\textsuperscript{73}

The first formal name for the epidemic was, as mentioned, Gay Related Immune Deficiency, or GRID. The syndrome was determined to be due to immune deficiency because of the cryptosporidium bacteria was determined in the lab to be the cause of gay bowel disease.\textsuperscript{74} This bacterium previously had only been seen in severely immune compromised patients, so the physicians began to examine immune level indicators in the body, such as lymphocytes. At this point, we know that AIDS can affect any person regardless of race, gender or sexual orientation. However, during the early year of the epidemic it was overwhelmingly gay men that were getting sick from the virus. For that reason, all of the doctors did not feel that the nomenclature was homophobic. Dr. Craig Keyes, a member of both the NYC gay and medical community, had the following to say about GRID:

I didn’t find GRID offensive. It was a descriptor. There was just so much confusion about it at first. It wasn’t entirely cleat that it was a viral infection initially. In fact everybody thought it was caused by poppers.\textsuperscript{75} Then they finally realized that it was blood borne and there was a big panic.\textsuperscript{76}

\textsuperscript{73} Ibid.
\textsuperscript{74} Michael DeVita, interview by author, November 3, 2013.
\textsuperscript{75} Poppers, an inhalant drug, was popular amongst people of the gay community and was initially seen as a potential cause of the disease.
\textsuperscript{76} Craig Keyes, interview by author, February 5, 2014.
Eventually the epidemic spread to people outside of the gay community, largely to hemophiliacs receiving blood transfusions, Haitians and injection drug users. The initial gay-specific nomenclature was no longer a sufficient descriptor. AIDS was given its current name by federal bureaucrats, an investigative team from the Center for Disease Control, and gay community leaders in Washington on July 27, 1982.77

Several of the physicians working in New York City during the first year of the epidemic remember the different labels the immune deficient syndrome was given before it was given the current name of Acquired Immune Deficiency Syndrome. However, they claimed that the overtly homophobic nomenclature was less prevalent in NYC hospitals than Treichler leads us to believe. Most doctors only heard “Wrath of God” rarely, and such words were generally scoffed on for their lack of scientific motivation. Dr. Sanders recalled such discourse, saying,

I think there were people then and there are people now who thought that HIV was a punishment for something – I mean it never made sense to me. That’s not the way science and infectious disease works. We’re not punishing anybody. Its genetics and epidemiology and that’s what won the day.78

Dr. DeVita could only recall one instance of such bias. In St. Vincent’s, many of the earliest AIDS patients were identified as having “gay bowel syndrome,” so named because of a gay male-specific demographic and similar symptoms – bad diarrhea that caused people to waste away. Nonetheless, some of the early names for the disease did mark a specific population and thus had real repercussions, such as political policy and health literacy of the general public.79 It

78 Keith Sanders, interview by author, December 27, 2013.
was hard to get the general public and moral majority leaders such as Ronald Reagan to pay attention to a disease marked by nomenclature to only impact gay men.

Though the early of the names for AIDS may not have been as homophobic as previously thought, it is evident that homophobia did exist in the hospitals in America. The history of the relationship between the gay community and the medical community that cared for them through the epidemic was tumultuous at best. The epidemic hit the gay community at a moment when the Gay Liberation Movement had just gained them a place in society. The Stonewall Riots, which occurred on the night of June 28, 1969 in Greenwich Village, is often attributed to the naissance of the modern gay right movement.\(^80\) This was only twelve years before the onset of the AIDS epidemic. Within the medical community, homosexual behavior was defined as a mental disorder in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and treated with shock therapy and even lobotomy until May 1974, just seven years before the epidemic struck the gay community in New York City’s Greenwich Village and San Francisco’s Castro.\(^81\)

It was not uncommon for the disease to be seen as a just punishment for the promiscuous homosexual behavior that was central to the politics of gay liberation. Many of the physicians mentioned that they heard such sentiment on occasion. Dr. Maria DeVita noted that she experienced it in the physicians lounge.

It was definitely not hospital wide. I think it was just a few people in the doctors lounge sort of making snide remarks type thing, but I definitely heard it more than once. I don’t think it was the prevalent thought process.\(^82\)

Most publications about the AIDS epidemic, especially those by queer theorists, highlight homophobia as a large social challenge.

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\(^80\) *Stonewall Uprising*, directed by Kate Davis and David Heilbroner (Public Broadcasting Service, 2011).
\(^81\) *Ibid.*
\(^82\) Maria DeVita, interview by author, January 25, 2014.
The challenge of homophobia in medicine was relatively small in New York City compared to other parts of the nation. Gay liberation had its roots in New York City and therefore the city’s queer community was more established and visible than most other parts of the nation aside from San Francisco. Doctors in New York City, as citizens working in one of the most heterogeneous cosmopolitan areas in our nation, if not the world, were exposed to the whole spectrum of the human experience while working the New York City. Thus, their perspectives towards the patients they were caring for was different not only compared to medical professionals trained and working in other parts of the nation, but also compared to their colleagues in different parts of the city itself. For example, in St. Vincent’s Hospital in Greenwich Village, gay men were a large proportion of not only the patient population, but also of the hospital staff. Dr. Dennis Greenbaum remembered what the large gay population in Greenwich Village and New York at the time, and how that shaped the presence of overt homophobia in the hospital setting.

It’s very difficult for me to comment of homophobia. Being in the middle of Greenwich Village at that time, and now that I’m not there anymore, being in New York City, I can’t even think of a physician who I would know that might be homophobic. It might be true in the Midwest, but I don’t believe its true at all in New York City… I mean you can always find an occasional person- but I don’t think that adequately reflects what life or medical care is in NYC, and especially back then in Greenwich Village.

He went on to note the presence of “out” gay men amongst the ranks of doctors and other hospital staff, which in turn, made the epidemic even more tangible for the doctors combatting the epidemic.

We were in the West Village, which was not only a place where gay men lived; they sought work in that area so they would be close to home. We lost a lot of staff people and we lost a lot of neighbors. My next-door neighbors had four men in the apartment and they all died. Especially if you lived in that area and had a lot of contact in that area, you lost a lot of friends. There were a lot of memorial masses to go to…. Here were

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83 Dennis Greenbaum, interview by author, December 18, 2013.
coworkers who were dying – people who they worked with for years. So I think that most people, even back then, had an open enough mind to not blame people for being gay. These were their friends, their whole experience.\textsuperscript{84}

As if seeing many patients dying is not enough, seeing a coworker and friend fall victim to an epidemic was devastating for some. It made the physicians all the more cognizant of the horrors of AIDS and committed to being more dedicated to combatting the epidemic. From the perspectives of the doctors interviewed, homophobia was more of the exception rather than the norm within the hospitals of New York City. This could be due to a multitude of reasons, most likely the nature of New York City itself: a melting pot of various races, ethnicities and cultures. All of the doctors interviewed in the study struggled to remember overt examples of homophobia within the hospital. However, there is still the opportunity for bias to erupt in less obvious ways, as exemplified in the formation of quarantined AIDS wards as mentioned before.

Promiscuity amongst members of the gay community was certainly seen as a social challenge. Physicians, especially those who reached out to at risk communities in New York City, educated on ways to reduce risk of transmission once that knowledge was available. However, many physicians commented on the success to grassroots gay community initiatives, such as the Gay Men’s Health Crisis, Inc. (GMHC). GMHC was based in New York City and had a large role in developing safe sex strategies that helped the gay population survive the epidemic. They provided emotional support, supported research fundraisers, and educated the public on safe sex practices and general HIV & AIDS awareness.\textsuperscript{85} The GMHC knew the community and worked openly gay health care professionals to develop new strategies to help

\textsuperscript{84} Dennis Greenbaum, interview by author, December 18, 2013.
\textsuperscript{85} Ibid.
fight the epidemic as well as to get gay relevant health information out to not only gay men, but also heterosexual men and women as well as injection drug users.\textsuperscript{86} It is interesting to note that while promiscuity contributed to the spread of HIV amongst the gay population in New York, it has been theorized as one of the saving graces of the gay community. Queer theorist Douglas Crimp, in his work “How to Have Promiscuity in an Epidemic,” challenges the widespread belief that the gay population is to blame for the spread of AIDS. He asserts that while promiscuity may have contributed to the rapid spread of what would become known as the human immunodeficiency virus, it eventually became the saving grace of the gay community. The gay community, so used to openly discussing their sexual interests and practices, when faced with a sexually transmitted communicable disease, were able to devise new strategies that enabled them to keep the virus at bay.\textsuperscript{87} Crimp says,

> We were able to invent safe sex because we have always known that sex is not, in an epidemic or not, limited to penetrative sex. Our promiscuity taught us many things, not only about the pleasures of sex, but about the great multiplicity of those pleasures. It is that psychic preparation, that experimentation, that conscious work on our own sexualities that has allowed many of us to change our sexual behaviors – something that brutal “behavioral therapies” tried unsuccessfully for over a century to force us to do – very quickly and dramatically.\textsuperscript{88}

Crimp attempts to flip the existing discourse about gay promiscuity on its head. Instead of blaming it for the rapid spread of HIV, he asserts that the gay community’s openness about sexual desires, which is taboo in most of society, allowed them to develop strategies to for safe sex.

As stated previously, overt homophobia in New York City hospitals was more of the exception rather than the norm. Many of the doctors were actually happy about interacting with gay patients because of the community’s mobilization. One of the biggest successes of the gay

\textsuperscript{87} \textit{Ibid.}, 253.
\textsuperscript{88} \textit{Ibid.}
community’s response to the epidemic was the community knowledge of the disease. The community worked to be up to date on the latest discoveries about the virus, treatment, and clinical trials for treatments.\(^89\) This was at first a challenge for many of the medical professionals. Suddenly, patients were questioning their physicians about their treatment strategies. No longer were physicians able to just dictate what was happening.

With patients who knew more about their illness than ever before, the dynamic of the caregiver and patient changed forever, which was both a challenge and a lasting improvement in health care. The patients were able to take agency in their health and engaged with their caregivers on treatments. Dr. Craig Keyes noted the change of the patient dynamic as one of the lasting legacies of the AIDS epidemic on the medical community at large.

I think it forced the medical community to have to work with a higher proportion of patients who were really smart about their condition. It forced the medical community in particular to act more in a partnership than in a kind of a more dictatorial frame of mind. I think that was a good thing for medicine.\(^90\)

Not all doctors were so thrilled to have such knowledgeable patients. It completely deconstructed the previous dynamic of caregiver and patient, making it a more egalitarian dialogue. AIDS’ legacy even translated into the broader medical community and in medical education in the United States.

The significant effect of AIDS, then, is that a more cooperative model has become normative (at least in medical rhetoric) and has been incorporated into medical school curriculums. This changed conception of the doctor-patient relationship has also been linked explicitly to an emergent understanding of the appropriate researcher-subject relationship. Patients have a "participant's interest" in clinical research that extends beyond the mere protection of their "rights" as "human subjects"; communities have a stake in the review of research protocols that is not satisfied by the token request for their "input."\(^91\)

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89. *How to Survive a Plague*, directed by David France (Public Square Films, 2012), DVD.
90. Craig Keyes, interview by author, February 5, 2014.
In this way, the new egalitarian dialogue continued not only in the hospital, but also in the research and medical school setting.

Many of the doctors also experienced the challenge of discussing with patients that they had a terminal illness. For many, this was the greatest challenge that they faced, and such interactions are still very vivid in their memories. Dr. Keyes remembered this as the one of the hardest parts of his time caring for AIDS patients in New York, many of whom he had known personally as friends in the West Village gay community.

For me the most difficult moments were talking to a patient who didn’t want to die. We had to talk about what we would do if we weren’t successful and that’s how we were going to work together and manage it all.  

Dr. Zeale had a similar experience with such conversations. When asked what first comes to mind when he thinks of the AIDS epidemic, he spoke of one instance of delivering the horrible prognosis.

It was a very difficult case – a young girl. I was attending, so it was probably around 1986 or 1987. She was the daughter of a patient of mine, and she was probably around 18 or 19. She came in with certain symptoms of again fever, sweats and I actually ended up having to do an HIV test and it ended up positive… This was her first sexual contact according to her and she eventually did die several years later. I can vividly remember sitting down with her and her mother and telling her this, and it was quite difficult.

These conversations were a challenge for both who entered them, physicians and patients.

With death all around them, an overwhelming sense of frustration and futility came over the doctors. They were constantly losing patients, friends and coworkers to a disease that was completely out of their control. After months fighting the epidemic turned into years, the emotional work took a toll on the physicians.

I’m not good at disassociating, just going there and doing it and leave. I’m sort of pretty attached to my patients; sort of wear my heart on my sleeve type thing, so I always found

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92 Craig Keyes, interview by author, February 5, 2014.
93 Peter Zeale, interview by author, January 11, 2014.
it very exhausting. But you know it’s just what I did, you try to make the best of it and
then you sort of just moved on with everything – but it was definitely, I mean I guess you
can have some sort of compartmentalization of it, but I think as you got to know people
and you have connections, social connections with that person, and then friends of the
people would come it, so it definitely had an emotional toll – I mean it wears you down.
You know it’s not good to keep taking care of people if they’re all going to die. It’s
really sad.\textsuperscript{94}

Dr. Greenbaum noted that many of the hospital workers themselves contracted the disease,
which had a taxing effect on the medical workers, he said “the impact on their coworkers was
horrible because they were being lost. Here were coworkers who were dying – people who they
worked with for years. So I think that most people, even back then had an open enough mind to
not blame people for being gay. These were their friends, their whole experience.\textsuperscript{95}” Many of the
physicians grew sick of spending so much time and energy focusing on a single disease that they
could not control when they were trained to quell thousands of diseases.

The physicians met the challenge of emotional work through community support. Many
of the interviewed physicians expressed the sentiment that their colleagues provided the strength
to continue working in the midst of such devastation. Dr. Maria DeVita spoke on her colleague
Dr. Craig Keyes impact on her. She said, “Craig didn’t have any fears about it and he was sort of
overwhelmed even at the time about – some of his friends would come in and his brother was
sick so I indirectly identified with him. I said well if Craig can do it than I can do it.\textsuperscript{96}” Dr.
Sharon Kiely shared this sense of community at St. Vincent’s Hospital, where she mentioned her
colleagues would help her cover rotations when there was an overwhelming amount of
admissions. While she was pregnant, Kiely mentioned that her colleagues would even offer to
perform risky procedures in her stead. She said, “At other times, colleagues of mine offered to do
certain procedures for me because I was pregnant. It was one thing to put yourself in risk as a

\textsuperscript{94} Maria DeVita, interview by author, January 25, 2014.
\textsuperscript{95} Dennis Greenbaum, interview by author, December 18, 2013.
\textsuperscript{96} Maria DeVita, interview by author, January 25, 2014.
doctor, but another when you’re carrying a baby. My environment was very supportive of me having a child.” Such a support system was certainly vital when working in the center of an epidemic like AIDS, for the physicians needed to stay strong for their patients. The physicians needed to keep their own emotions at bay to provide emotional support.

The difficulty of these discussions translated into another challenge that the doctors faced: disclosure. Physicians take very seriously the notion of patient-doctor confidentiality. With such privacy in place, trust can be in place for effective treatments to occur. An issue that physicians faced with AIDS was the stereotype that it was a gay disease. As mentioned previously, the epidemic was largely confined to the gay male population during the early years of the epidemic, which is why names such as “Wrath of God,” Gay Bowel Disease, and GRID came about. Thus, an AIDS diagnosis during the early years of the epidemic essentially carried with it the idea that the patient was gay. In this way an AIDS diagnosis was often accompanied with the patient “coming out,” whether he wanted to or not. Therefore, an AIDS diagnosis was taken very seriously and secretively on multiple levels: not only was it a death sentence, it was also stigmatized because people feared catching it and because it implied that the person had engaged in homosexual activity. Dr. Michael DeVita recalled talking to patients and family about being open with their diagnosis.

A lot of them hadn’t told their parents that they were gay let alone sick. It made it tough….It was hard because you want to be honest and people have the right to not present their sexual affinities. Normally it wouldn’t be an issue. I mean, I was not telling families that their children were gay for years – that wasn’t the issue. The problem was that now their sons were dying and families wanted to know why their sons were dying and if you say he’s dying of AIDS, they know he’s gay. If you say he’s dying of pneumocystis, they know he’s gay, and it became an issue.97

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Such was the case with the Hollywood superstar Rock Hudson, which brought the epidemic to the forefront for large amounts of America.

Physicians worked with their patients to tackle this challenge, encouraging them to tell their families themselves. Some of the doctors noted their roles changing from a dispenser of medicine, to a more holistic approach, serving not only the biomedical needs of the patient but also their emotional needs. Dr. Craig Keyes noted AIDS illuminated where American medicine could be improved.

I think many more doctors became more open to the idea that American medicine didn’t have the market cornered on providing aid and comfort. I think it really helped understand the prospects for a more holistic approach to medicine. By holistic I mean taking care of the whole person: the spiritual part, the emotional part, not just the physical.

Almost all of the doctors interviewed, when asked about their general thoughts of the epidemic, remember such conversations with their patients.

**Challenges Associated with Injection Drug Users**

Not all AIDS patients were the same. Each presented new challenges towards treatment. Various factors impacted the way the epidemic spread within the different populations such as different risk behaviors, socioeconomic status, government policies affecting them, cultures, stigmas and mean education levels. In light of these factors, AIDS response was adapted to the needs of each community. Dr. Keith Sanders noted the difference between the treatment of the first two at-risk populations, men who have sex with men (MSM) and those who use drugs intravenously. He even pointed out that different opportunistic infections manifested in the at-risk groups.

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99 Craig Keyes, interview by author, February 5, 2014.
Well the injection drug users were very much prone to bacterial blood infections. There really was another epidemiology of infection in those patients than in the sexually acquired HIV patients.\textsuperscript{100}

Because a solid antiretroviral regiment was not available in 1995, such bacterial infections were extremely serious.

Injection drug users, like the gay community, occupied a fringe position in the society of the greater United States. However, unlike the gay community, they were held in an especially low regard even in New York City. Dr. Craig Keyes noted that these patients were held to a much lesser regard than most other AIDS patients, and definitely the gay patients. Such a divide in attitude could be due to a multitude of issues, but some attribute it to a differentiation of class.\textsuperscript{101} The medical professionals are accustomed to a middle and upper class standard, which made it difficult to connect with patients on the underside of society. This manifested itself in how doctors approached treating them within New York City hospitals. Dr. Peter Zeale remembered the challenges that injection drug users presented to those who were in charge of their health.

Often times they would want more drugs. They would be more nasty to you. A lot of the time they would sign out of the hospital against medical advice and in all honesty you were happy to get them off of your service. They were often times more trouble than they needed to be. Looking back at those patients, I would say that we did treat them differently. I think we had less tolerance and we would love to get them off of our service.\textsuperscript{102}

For some, the hospital was the first exposure to injection drug use and addiction. Dr. Keith Sanders remembered what it was like facing patients with addiction for the first time. He saw the injection drug users as a completely different challenge when treating AIDS patients.

\textsuperscript{100} Keith Sanders, interview by author, December 27, 2013.  
\textsuperscript{102} Dennis Greenbaum, interview by author, December 18, 2013.
I mean with the injection drug users you had two diseases already. You had the viral infection and then you were dealing with addiction that was difficult to break. We were not able to treat the addiction…I remember one specific time when a patient was not in his room and was found dealing or buying drugs in the public area down the hall. We were so naïve, like “holy crap! He’s a drug user!” Well duh – that’s why he was in the hospital. We were surprised that he continued it in the hospital, but he was addicted. That’s what addicts do.103

Dr. Sanders’ comment sheds light on how IV drug users were harder to stabilize from a medical perspective. With the black market, there are a multitude of medical risks, such as the lack of access to clean needles and unregulated exchange of narcotics, which are often impure and “cut” with a variety of fillers to increase the profit of the drug dealer. The combination of dirty needles, narcotics and fillers makes injection drug use very risky, especially for a patient with a suppressed immune system, such as those with AIDS.

With immune suppressed patients injecting themselves with who knows what both in and out of the hospital, medical professionals were left completely unprepared to combat the specific needs of a patient population so marginalized socially and legally. As the decade progressed, the medical professionals learned to ask specific questions catered to their experience as an injection drug users. In McGarrahan’s study one nurse stated,

Say I go in, and I find a patient who’s acting a little strange, whose mental status is a little off and I’m trying to decide, “Did he just get high or does he have a central nervous system infection?” I had this situation when I was doing home care. So I asked him, “Did you just shoot up? I need to know whether to call the doctor.” And he said, “Yeah.” So I said, “What did you do?” In this case, he has shot heroin and cocaine mixed together, which they call a speedball on the street, and his pulse is 150. I had just taken his pulse, and I had to say, “Tell me what you did, because otherwise I have to get an ambulance because your pulse is 150.”104

These questions were very stigmatized and left unasked. However, as time went on more and more injection drug users came into the hospital, the medical professionals became more familiar

103 Keith Sanders, interview by author, December 27, 2013.
with the previously invisible underground drug culture. With this exposure, medical professionals became more comfortable with asking the questions that they previously thought were awkward to ask.

Such questions are seen as one of the lasting legacies of the AIDS epidemic. Before the epidemic, physicians did not ask culturally sensitive questions. However, they are now commonplace in a medical evaluation because these sensitive social questions have biomedical implications. Dr. Peter Zeale shared this opinion, discussing how he could make a more informed diagnosis while probing with these questions.

We always question people’s drug use and sexual habits because you never know when someone presents in your office with a febrile illness. Could it be HIV? So it makes you delve a little more into those questions, which I think are reasonable questions to ask….In those patients that have infectious illnesses, I think it has taught me that yes its always a possibility just like you think now days when you see a patient that is sick and do they have Lyme’s disease? It comes down to some strange symptoms patients have. You always say umm is it Lyme’s disease? But in febrile patients who are ill for a while, I think you always have to question, could it be HIV?105

The AIDS epidemic pushed physicians to tackle socially sensitive questions, which allowed them to make more informed inferences and deliver more specialized care.

In addition, different public health organizations initiated needle exchange programs in the late 1980’s to prevent the transmission of HIV through shared dirty needles.106 Dr. Michael DeVita remembered physicians advocating such medical services within the medical community.

Joyce Wallace was a leader nationally and locally in promoting needle exchanges (and condom use). In both cases, Joyce argued that even our vices, however grievous, should not be a death sentence. She argued that ethically and morally we owed it to humanity the help to prevent death from social vices, and hope later for the person to be ready to recover. This is a version of addiction is a health issue, not a moral or legal one. I think she had it right, and was decades ahead of the curve.107

105 Peter Zeale, interview by author, January 11, 2014.
Physicians who advocated for such programs were certainly open minded and progressive. At the time, legislation restricted any federal funds from being spent on outreach that condoned IV drug use. This public health service was very controversial at the time.

However, the challenges associated with injection drug users were not limited to chemical dependence. The injection drug use, being illicit and stigmatized in American society, carried with it many social implications. These patients did not have the same support system that regular, or even homosexual patients had. Though it was common at the time for both injection drug addicts and gay patients to have poor relations with biological families, gay patients had other forms of kinship. Gay patients had a cohesive and very supportive community that mobilized around the AIDS epidemic over the course of the 1980’s. The injection drug users did not have that benefit. They had limited social ties to friends and family out of the nature of their addiction.

In some senses, this is one of the short fallings of the medical response. They did not have adequate methods to address addiction or a social safety net for those without kinship structures. This was a point that some of the doctors struggled most with when treating the AIDS patients with addiction to intravenous substances. Multiple of the interviewed doctors stated their discontent with patients because they kept asking for analgesics, or pain reducing drugs, such as opiates like morphine. Dr. Sharon Kiely expressed her personal experience with drug addicts.

They used to call, making up excuses as to why they needed more pain medication. They would say that their doctor told them to call you. When we would tell them to go to the emergency room, they would say that they cant. As time went on, they realized who were the “easy doctors,” who would prescribe medications less strictly, and the times they would be on call. I was very tough, so they stopped calling me.108

With injection drug using patients asking them for more narcotics, doctors naturally became less sympathetic to the plight of injection drug using patients. However, they were not equipped to combat the addiction itself. Effective methods for reversing drug addiction were not discussed in length in medical training.

The AIDS epidemic was unique in the way that it only affected certain stigmatized groups at a moment of American history when there was a resurgence of conservatism. A stigma emerged around the disease itself. The physicians were now faced not only with biomedical challenges, but also social ones. They adapted to challenges presented by the stigma of the disease and the marginalized groups affected by it. Exposure to these groups made them more equipped to handle their individual needs, both biomedical and emotional. They created community-based health outreach, made the physician-patient dynamic more egalitarian, began to ask more culturally sensitive questions to provide more specialized outreach and began to take a more holistic approach to medicine to meet more of the patients’ needs. These amendments had a lasting impact on American health. As the next chapter will show, law codified some of the public attitudes toward the marginalized groups most affected by HIV that were discussed in this chapter. With AIDS spreading and inadequate policy, the physicians had to react to the politics of the epidemic to provide the best care for their patients.
CHAPTER 3: CREATING CHANGE: POLITICAL CHALLENGES

It is no doubt that the early AIDS epidemic was certainly surrounded by a great deal of politics. The political challenges surrounded codified laws, rules and policies that often were rooted in the social challenges discussed in the previous chapter. Hospital, municipal, state and national policy affected those impacted with HIV and the physicians who cared for them. Some of the physicians were overburdened with work and did not pay attention to the politics of AIDS. Some actively sought to address the political issues that arose from the epidemic, and others were forced to confront the political action because it came to them based on where they worked. For those of the physicians who faced in the political unrest that AIDS brought about, it is agreed that the politics of AIDS was certainly a unique challenge for those working in medicine. The physicians adapted to health policy that was slow to react to the growing epidemic. They adapted by actively engaging and amending hospital policies and filling the void left by late city and national governmental action.

**Hospital-Level Politics**

Of the doctors interviewed, most did not seek to engage in politics. In fact, many were unaware of most of the politics about the disease.

Quite honestly we were mostly self-absorbed and concentrating on what we had to learn, etc. [St. Vincent’s] was not really a place having a lot of exposure to public health or public health awareness or even much awareness of what was going on in the world or the news period. People were just busy working hard in their own craft, etc.109

The sentiment of being consumed by their own work was not limited to just Dr. Zeale. Almost all of the physicians mentioned how busy they were during that period because of the influx of patients.

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As the decade progressed, hospitals were getting more and more crowded. The doctors had trouble juggling all of their responsibilities for regular patients with the confusing and ever-changing needs of AIDS patients. Dr. Kiely commented on the scale of work she was faced with, saying that she could expect to stay late after each shift those days.

It was exhausting because where I was working, the hospital was busting at the seams. . . You would admit patients at night and it was nothing to admit 25 patients a night on call. Now, the residents are capped at 8 or 10. They can’t take anymore. At 10 they’re capped for the night I remember one night I had 30 admissions. I had 30 admissions on my side of the hospital and the hospital was split into two teams. You could be on the Colman building, which would be the new fancy building or on call for the wards. There were two teams on at night. I remember the night it hit 30; I couldn’t see all of those people. I was moving as fast as I could. My friend who was working on the other side came over and helped.¹¹⁰

Dr. Greenbaum also noted that between 1981 and 1985, one out of every six patients diagnosed with HIV in the United States were diagnosed at St. Vincent’s hospital alone.¹¹¹ The epidemic was huge in New York City.

With AIDS patients filling up the hospitals as well as heightened stigma around the AIDS, the political issue of quarantine came into question. At one point in the epidemic, the numbers rose so much that there was serious discussion about quarantining on a citywide level. Dr. Dennis Greenbaum remembers how the city of New York even considered devoting a full hospital for the care of AIDS patients.

In the mid 1980s we had an 8 bed ICU in the Department of Medicine at St. Vincent’s and we had an average of 6 patients of 8 beds belonging to AIDS patients. There was a lot of thought of identifying a concentrated hospital so that a hospital – I think they were talking about Cabrini hospital – could become New York City’s AIDS hospital. Then once a patient was reasonably stabilized the patients could be moved to one place because there was no room for any patients other than AIDS patients when the volume was so high. But then once we realized that certain forms of isolation were unnecessary, the fear went down, the volume of patients went down.¹¹²

¹¹⁰ Sharon Kiely, interview by author, January 4, 2014.
¹¹¹ Dennis Greenbaum, interview by author, December 18, 2013.
¹¹² Ibid.
The fact that it was even considered that an entire hospital should be devoted for just a single infectious disease paints a picture of the scale of the epidemic in New York City. It also points to the stigma that surrounded the disease. People simply did not want to be treated next to AIDS patients.

Quarantine on a citywide level was not the only response to the high volume of HIV patients. The influx of AIDS patients caused intra-hospital debate as well. For example, some physicians fought for more compassionate policies for AIDS patients in the hospitals. As the decade progressed, more information about the human immunodeficiency virus came up and it began clear how the disease is transmitted. The progression of the infection and development of AIDS also became common knowledge. However, one thing that changed fairly slowly was control of the virus itself. Doctors were able to care for an AIDS patient’s opportunistic infections, but could not combat the disease. Some doctors suggested making it possible for AIDS patients to leave the hospital. Dr. Michael DeVita remembers the crowded wards at St. Vincent’s hospital and the responses of some physicians.

We wouldn’t sleep. We were trying to make room for the patients because the hospital was being flooded with patients with AIDS who were going to die. We were campaigning/ trying to get the patients taken care of in a way that wouldn’t require them to be in the hospital. We wanted them to be able to stay in a nursing home or their own home because there wasn’t much we could do for them in the hospital.\footnote{Michael DeVita, interview by author, November 1, 2013.}

Though the notion of sending a patient home may sound like giving up, the thought was actually much more altruistic. With no drugs effective at fighting the virus itself, it seemed to the patients benefit to occupy a more comfortable space than a hospital with the manifestations of the epidemic all around them: overworked medical staff, crowded wards, death and sadness. The physicians operating the in the intensive care unit (ICU) at St. Vincent’s pushed to amend
medical response to AIDS patients in the ICU so that they could make patients more comfortable as they died. Dr. DeVita said, “The idea was to rescue dying patients with a face mask therapy instead of an endotracheal tube (down the throat, 100% mortality back then), and with the time we bought using that therapy, discuss end of life options with them.” In this way, the physicians fought for the comfort and dignity of their patients.

With perceived fear of getting infected by HIV while caring for AIDS patients, there were also debates at the hospital level concerning risk to medical staff. The doctors had varying amounts of fear when caring for AIDS patients. In the early years of the epidemic, no one knew how the disease was transmitted. Some medical professionals refused to enter into the rooms of AIDS patients, and others even quit, though both were fairly uncommon. Though this is based on fear of personal risk, it is certainly a political statement. Dr. DeVita recalled such fear within St. Vincent’s Hospital.

Everybody was concerned. There were some people that were so concerned that they wouldn’t even go into the patients’ rooms. So there were some people who were very very worried, and there were people who just didn’t care.

The physicians interviewed in this study all expressed a heightened caution when caring for patients and the odd case of someone refusing to care of an AIDS patient out of fear. However, this was not as large of an issue as is perceived in much of the political discourse of AIDS.

Though such protest was infrequent, hospitals like St. Vincent’s adopted new rules to prevent such actions.

The hospital actually made a policy that you couldn’t refuse to care for patients. You would be fired for doing so. This came about because it was a Catholic hospital and they

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114 Michael DeVita, interview by author, November 1, 2013.
115 Michael DeVita, interview by author, November 1, 2013.
wanted to take care of people. The policy came about in the midst of aids as soon as they found out about it. There was a bit of discussion, but they stopped it.\textsuperscript{116}

Institutional regulations, in the absence of larger medical policy, prevented protestations of caring for AIDS patients to a halt.

A larger political issue within the hospitals themselves was over the use of excessive medical precautions. As more and more information about the human immunodeficiency virus became clear, debate arose amongst the doctors caring for AIDS patients about the use of medical gowns. The extensive medical biohazard precautions did have an effect on both medical workers and patients alike during the epidemic. The garments had an alienating affect on patients who already experienced multiple levels of bias and social stigma. As more and more information about the virus surfaced through research, doctors began to speak out against such extensive precautions. Dr. Michael DeVita remembered a colleague of his at St. Vincent’s Hospital, Joyce Wallace, who spoke out to increase the quality of AIDS patient care. He said, “Joyce thought it was immoral to wear gloves and masks and gowns because people were dying. They needed humanity and not sterility.\textsuperscript{117}” Doctors attempted to make the gowning procedures less prevalent by changing the social conditions. Through widespread disapproval of the unnecessary precautions, they became less commonplace. Dr. Sharon Kiely remembered questioning her chief resident, her superior at St. Vincent’s on his gown usage.

I had a chief resident who I got in a lot of trouble because he was a dweeb. One night we went into the room of a patient being admitted with AIDS and at that point we knew you didn’t need to dress up like a man going into outer space. This doctor had a mask, goggles, hair net – I mean he looked like a cartoon character. He said I needed to gown up to go into the room, and I asked “why?” even though he was my superior. He was just a jerk. That was unusual.\textsuperscript{118}

Over time, the gowns became less common in the AIDS wards.

\textsuperscript{116} Michael DeVita, interview by author, November 1, 2013.  
\textsuperscript{117} Michael DeVita, interview by author, November 3, 2013.  
\textsuperscript{118} Sharon Kiely, interview by author, November 6, 2014.
At the time, some hospitals had conservative policies concerning sexuality. St. Vincent’s, though it was a hospital in the West Village, was Catholic. Though this did not affect most treatment within the hospital, it did impact certain sensitive conversations that impacted health, such as those associated with marriage and sexuality. Dr. Sharon Kiely remembered one instance of this, as she was getting her vaccinations updated.

When she gave me the shot, she said, “Well I know you’re newly married, but you can’t have sex for three months now after this shot.” I was like, “what?” But I later realized that what she was saying was that you couldn’t get pregnant for three months. But in her mind there was no birth control and so you can’t have sex. That’s what that was about – it wasn’t that you couldn’t get pregnant. If I were single, she wouldn’t have told me anything. They treated you as a patient with church doctrine.\(^{119}\)

Such policies also impacted what could and could not be prescribed in the hospital. Due to the laws of the Vatican regarding contraception, hospital workers were not allowed to prescribe or distribute condoms in the hospital. From a public health standpoint, such policies heightened potential for HIV transmission, especially for high-risk groups like sex workers and the gay community.

Hospital workers on different levels reacted to the needs of the community in defiance of such protocols. The hospitals had nuns, the Sisters of Charity, which were very proactive for the AIDS patients at the hospital. Dr. Michael DeVita remembered the outlook of the nuns operating in the hospital.

St. Vincent’s was a very respectful place. It was Catholic, but respectful trumped Catholic. It was thought of as a mission district hospital. Half the physicians there were gay, but the nuns there were really special. They would be walking around helping all the time and they were the most tolerant, wonderful people. They would have been excommunicated if they were found promoting condoms and stuff, but they did it because they knew it was the safest thing they could do for the people. They cared more about the people they were working with. It was their mission to try to save lives – it was not their mission to try to get people to convert.\(^ {120}\)

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\(^{119}\) Sharon Kiely, interview by author, January 4, 2014.

\(^{120}\) Michael DeVita, interview by author, November 1, 2013.
However, the Sisters of Charity at St. Vincent’s were not the only people working at the hospitals who took such actions. The physicians themselves would even prescribe condoms, which was very important for people of lower socioeconomic status like the marginalized groups most at risk for AIDS and the homeless population of downtown New York City.

We would prescribe condoms, which was against the rules of the church. Yeah because [prescribed condoms] were covered for people with public assistance. St. Vincent’s did not approve of us doing that, but we did.121

This was also risky because prescriptions are always linked to the physicians who sign for them. Doctors would get in trouble for such action. Such defiant action – putting job security on the line - is a less obvious form of political protest in the hospital itself.

Politics Outside of the Hospital

Although most of the physicians that were interviewed did not engage in direct political action, the context of the epidemic and their location at the epicenter forced them to interact politically in one way or another. At a citywide level, the physicians working in New York City hospitals were indirectly affected by political agendas in the form of policies as well as direct political confrontation in the form of protest. In addition, some medical workers did engage actively in the politics of the epidemic.

New York City’s response to the AIDS epidemic was surprisingly slow considering it was one of the epicenters of the North American epidemic. One of the main critiques of Ed Koch’s leadership as mayor of New York City was his poor handling of the AIDS epidemic. In 1984, three years into the epidemic that infected tens of thousands of New Yorkers, the city had

121 Sharon Kiely, interview by author, January 4, 2014.
allocated only $24,500 to AIDS response. As mentioned previously, city hospitals were overflowing with patients sick from AIDS and had limited resources. Such a lack of response on the citywide level made it more difficult to meet the needs of AIDS patients.

At the federal level, it is fair to say that early AIDS policy was not only inadequate in aiding quelling the epidemic’s spread, but also an impediment to delivering care. In fact, during the early years of the epidemic, public health entities like the CDC was even restricted in their outreach toward the high-risk populations. In October of 1987, Jesse Helms, a US Senator from North Carolina, introduced an amendment to a joint Department of Labor, Health and Human Services, and Education bill that allocated close to $1 billion to AIDS research and education. Just three days after the historic AIDS quilt lay on the national mall, Amendment number 956, which would become known as the Helms Amendment, began with the following statement of purpose:

To prohibit the use of any funds provided under this Act to the Centers for Disease Control from being used to provide AIDS education, information or prevention materials and activities that promote, encourage, or condone homosexual sexual activities or the intravenous use of illegal drugs.

Therefore, any public health entity receiving federal funds could lose them if they had programs geared for gay men or injection drug users. However, such poor response was not limited to Congress. The Reagan presidency, with its “moral majority” political backing, remains to be heavily critiqued for its lagging response. Reagan did not publically mention the word AIDS until 1987, six years into the epidemic that had already killed 21,000 and infected 37,000

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124 Ibid., 259.
Americans. In 1983, 95% of the US Department of Health & Human Service’s funding for AIDS research came from money already allocated to other health projects because Congress was unresponsive.

Dr. Craig Keyes was certainly cognizant of the politics of the epidemic, and commented on President Reagan’s response.

I hated him of course. I was really really angry… I think he could have said the word, for starters. He could’ve made it more of a priority to protect people who at that point were not infected. He could’ve made an executive order to alter the funding. Reagan was extremely skilled as a politician. He could’ve gotten more money, gotten congress to act in different ways than it did. He could’ve done a huge amount… I think that who suffered most were particularly IV drug users women and children. They had the lowest level of awareness of their potential risk and children didn’t have a prayer. Women who were pregnant and had HIV weren’t even aware of the risk for the baby. I think not having the funding to educate people and to screen and test sex partners at risk – particularly IV users who were men – I think that’s criminal. I felt that all along.

Within the AIDS activist community, Reagan’s AIDS response is dubbed “AIDSgate” (See Appendix I, Figure 3). Because the virus spread exponentially during the early years, government inaction is seen as murder itself because effective public health policy could have curbed the virus’ spread. Some see it as a systematic genocide. Keyes noted this pervasive sentiment amongst the gay community of New York. He remembered attending a performance of Kiki and Herb, a drag queen duo, at Carnegie Hall during which a performer said, “The saddest day of my life was the day Jon Hinckley missed,” to the response of an “enormous ovation.”

Left a gap in health access for marginalized communities due to policy that at best ignored the problem and at worst systematically made it worse, physicians took outreach into

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127 Craig Keyes, interview by author, February 5, 2014.
128 How to Survive a Plague, directed by David France (Public Square Films, 2012), DVD.
129 Craig Keyes, interview by author, February 5, 2014.
their own hands. As stated previously in the study, physicians like Joyce Wallace took it upon themselves to leave the hospital and engage with politically marginalized groups in the community, such as sex workers. In addition, Dr. Craig Keyes was able to gain a grant through the National Healthcare Service Corps to start his own clinic for AIDS patients on West 13th Street between 7th and 8th streets in the West Village. He worked to bring as many patients as possible into his clinic. Through such action Keyes and the other physicians operating in his clinic were able to care for the needs of the marginalized people entering his clinic, despite the lack of national and citywide policy.

Community organizations also rose to fill the void. The Gay Men’s Health Crisis (GMHC) formed to provide a variety of resources and support to the AIDS community of lower Manhattan. They were the oldest and largest AIDS outreach groups in the United States at the time of the Helms amendment, developing safe sex comics and disseminating AIDS information. Before the Helms Amendment, the GMHC had received $674,679 from the federal government. Dr. Dennis Greenbaum recalled the tangible impact that the GMHC had on the AIDS epidemic in New York City, specifically in Greenwich Village.

I think the response to the HIV epidemic was spearheaded by a group called the Gay Men’s health crisis (GMHC). The GMHC handled HIV in a way that other conditions rarely see. They took control of everything. . .They visited the men at home. They worked as social workers and like family to the gay men who didn’t have family. Some of [the AIDS patients] had moved from Middle America to Greenwich Village and here they were all dying. So the GMHC figured out ways of doing lots of things – fundraisers and helping to support research – so this community-based group unlike any other that I was ever aware of really took the disease by the horn. And they are clearly responsible for most if not all of the initial response to the epidemic, but they are still active and still support all of the services that HIV patients need.

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130 Craig Keyes, interview by author, February 5, 2014.
132 Ibid., 260.
133 Dennis Greenbaum, interview by author, December 18, 2013.
Such grassroots community groups certainly helped to meet the needs of AIDS patients, especially considering the lack of government policy.

**AIDS Activism**

While some physicians were not cognizant or too busy to engage in the macro level national policy, others sought it out. Dr. Greenbaum noted that some physicians participated actively in political organizations such as the AIDS Coalition To Unleash Power, which sought to redress the flaw in AIDS policy.\(^\text{134}\) ACT UP was primarily focused on raising awareness of HIV and AIDS, affordable and dependable treatment, changes to the methods of clinical trials.\(^\text{135}\) With more people dying every day, ACT UP used drastic tactics. They were notorious for staging protests designed to disrupt everyday life. They staged “die-ins” in churches, kiss-ins in hospital emergency rooms, and sit ins in pharmaceutical-companies.\(^\text{136}\) In fact, on October 11, 1988, ACT UP gained international attention for AIDS when they effectively shut down the Food & Drug Administration.\(^\text{137}\) Though the gay community certainly led the front of ACT UP, its membership appealed to many others, even physicians.

As stated, one of the main goals of AIDS activist groups like ACT UP were to make available effective and affordable treatment for HIV. AZT was the most expensive drug to ever be on the American market.\(^\text{138}\) This made the drug unaffordable to many. Many of the physicians did not work directly with the financial strain of pharmaceuticals and did not experience the drug’s unaffordability first hand. However, for those who worked in the community-level outpatient clinics, availability was an issue. Craig Keys, for example, remembered the scramble to get AZT within his AIDS clinic in the West Village.

\(^{134}\) Dennis Greenbaum, interview by author, December 18, 2013.
\(^{135}\) *How to Survive a Plague*, directed by David France (Public Square Films, 2012), DVD.
\(^{137}\) *Ibid.*
I was in a clinic that was able to dispense it and had a bunch, so I had access to it, but no it was not unlimited. I had a limited amount to give and if you ran out you were just out of luck. People who had insurance were ok, but its all the uninsured or under insured that had trouble.  

To respond to the many underinsured people with HIV, Dr. Keyes’ clinic attempted to secure more AIDS medication. They tried to attract as many patients as possible to gain the attention of pharmaceutical companies so that they would test new prescription drugs there. In this way, Dr. Keyes was able to secure the “biggest stash [of AZT] in the city by far.” Even though the stockpile was relatively large, it was still finite. The flow of medications was scrutinized to ensure that the available medications were used as efficiently as possible.

But oh no I remember very clearly it was tightly controlled and I had to approve any of the exceptions that people gave more than 2 weeks at a time. At the time you would think, why would you give them a months worth of medication if you’re not even sure they were going to live that long? That’s how crazy it was.

He mentioned that the drug was only released in little portions at a time and to specific people. He even had to put some aside secretly for others that would not otherwise have access to it.

Such measures stretched the resources as much as possible until the government stepped in. Dr. Kiely remembered how availability changed with the passage of the Ryan White Care Act by the US government in 1990. This grant allowed hospitals such as St. Vincent’s to apply for funding to make medical access more affordable for low-income AIDS patients.

Well I used [AZT]. We had Ryan White money and other things so we didn’t have any issues with people getting treatment. That was the good thing.

By utilizing public sector grants, physicians in New York had more freedom to prescribe the antiretrovirals.

\[139\] Craig Keyes, interview by author, February 5, 2014.
\[140\] Ibid.
\[141\] Ibid.
\[142\] Sharon Kiely, interview by author, January 4, 2014.
\[143\] Ibid.
Though Dr. Keyes did not engage actively in national politics, he and the other physicians in his clinic were confronted with the politics of the epidemic through appearances from ACT UP. In one instance, Keyes remembers Larry Kramer, one of the founders of ACT UP, coming to protest within his clinic.

Larry was just so angry at anybody who was working within any kind of infrastructure. He would come into the clinic and just start screaming at us because we were part of the federal health system and don’t you know Reagan is trying to kill everybody.144

Such protests in the medical setting were not isolated to just clinics. In fact, ACT UP even staged a “Kiss-In” in the Emergency Room of St. Vincent’s Hospital to protest the treatment of AIDS patients. Not all protests were as radical as Larry Kramer’s and shed light on real issues for AIDS patients. The hospitals would respond to such protestation through open discourse. Dr. Craig Keyes mentioned, “We would say, ‘We’re not trying to kill anybody, Larry. We were trying to help.’ But he was just nuts. I had known him from before and so it wasn’t that difficult.145” Hospitals such as St. Vincent’s would also openly negotiate with the leaders of ACT UP on how to improve patient care.146

Many AIDS activists critiqued the medical industry for having a slow response to the epidemic, claiming that the FDA and NIH research and approval processes were too sluggish to meet the short lifespans of many AIDS victims. However, many of the New York City physicians interviewed had the reverse sentiment, claiming that AIDS captured the attention of many. Dr. Kiely commented on the swiftness of AIDS medications in comparison to other common illnesses, saying  “I recall that a person without HIV couldn’t get medication for their heart disease, but you were able to get what you needed for people with AIDS.147”

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144 Craig Keyes, interview by author, February 5, 2014.
145 Ibid.
146 How to Survive a Plague, directed by David France (Public Square Films, 2012), DVD.
147 Sharon Kiely, interview by author, November 6, 2014.
earlier, the Chairman of Medicine at Lennox Hill described the epidemic as a “medical fad.” However, other doctors thought that the response could have been hastier if the resources had been mobilized earlier on a governmental policy level.

HIV/AIDS impacted specific groups of socially marginalized people, which transformed the epidemic into a highly charged political issue. AIDS politics arose within the hospital, at a city level, and at a national level. While some of the physicians did not pay attention to the politics of AIDS, others actively sought out to address the political issues that arose from the epidemic. Some were even forced to confront the political action because it came to them based on where they worked. The politics of AIDS certainly presented unique challenge for those working in medicine. The professionals adapted by actively engaging and amending hospital policies and filling the void left by late city and national governmental action.
CONCLUSION

In this point in history, the year 2014, America is in the 33rd year of the AIDS epidemic. Now, the epidemic has spread across the nation to all races and socioeconomic levels. There is significant federal cognizance and policy, both on a national and international level. HIV education is taught in all of the nation’s schools, and there is significant outreach to patients who test HIV positive. Moreover, there is Highly Active Antiretroviral Therapy (HAART) therapy, which has extended the life expectancies of HIV positive patients to be essentially equal to those who are HIV negative. The face of the HIV & AIDS epidemic has certainly changed from the early years of the epidemic, when an AIDS diagnosis implied certain death and HIV was only seen in marginalized groups in New York City and San Francisco.

As we begin to look back at the early AIDS epidemic, it has become increasingly important to monitor how the early epidemic is portrayed. The overall narrative of the early AIDS epidemic is constantly shifting with the rapid influx of scholarly work and mainstream media. This work has revealed a hole in the AIDS narrative. While the politics and the science of the epidemic is widely reported on, the narratives of the physicians – those who saw the epidemic play out in front of their eyes – has been absent. Such absence, in turn, has become clear in media portrayals of physicians in the epidemic, which have either demonized or sanctified the physicians who looked after AIDS patients.

This project has certainly transformed over the course of research. My dual background in the physical sciences and gender studies had given me two different perspectives towards the AIDS epidemic: one quantitative and scientific and the other political and historical. When I began to interview the physicians, my questions were designed to address the classist, racist and homophobic stereotypes of the American medical community I learned from my gender studies
readings as well as the biomedical issues I had learned in my biology courses. However, I quickly found out that these questions did not fit the narratives of the physicians I interviewed. It seemed that through interviews, I was able to see the human side of the epidemic. These physicians were not saints or demons, but normal people trying their best in spite of enormous adversity. Such moral absolutism in the portrayal of physicians in New York City during the early AIDS epidemic prevents us from seeing the true narrative of challenge and ingenuity. Though there was plenty of failure as the decade progressed, the physicians working in New York City progressed to meet the changing needs of their patients. Their efforts have changed the face of American medicine.

For the physicians who worked during the 1980’s in New York City, looking back at the AIDS epidemic was not easy. Even though the early period of the epidemic was over two decades in the past, all of the physicians still had vivid memories of patients, their coworkers and their own thoughts of uncertainty, fear and sadness. The compilation of the physicians’ stories in this study, though they differ in many ways, has revealed a common narrative of physicians who worked in medicine in New York City during the 1980’s. Their story is one of unique biomedical, social and political challenges distinct to AIDS. The physicians, over the course of the 1980’s, adapted to meet these challenges using methods that have become commonplace in American medicine to this day.

The first chapter of this study presented the massive biomedical challenges associated with the AIDS epidemic. These biomedical challenges for the physicians, such as HIV’s retroviral structure, unpredictable latency period, safety precautions, and a lessened work force, and new types of medications, were initially extremely difficult for the physicians to handle. As more and more information came out, the physicians adapted new methods to respond to these
challenges, such as implementing AIDS wards, developing treatment to increase immune function and fight opportunistic diseases, reframing the epidemic, and creating universal precautions to prevent transmission. Many of these developments are still important for American medicine today.

The second chapter of this study examined the social challenges that physicians were faced with while fighting the AIDS epidemic. The challenges were largely due to the types of groups that contracted the disease and the stigma associated with the disease. This epidemic, unlike others previously, did not impact all of society equally. Transmission was due to behavior, and it hit groups already marginalized by American society at a point in history when there was a resurgence of conservatism, embodied in the “moral majority” and Reagan era politics. A stigma around the disease itself arose. The gay men and injection drug users had different relationships with both the medical community at large, the politicians that drafted policy concerning them and, most directly, the doctors that were treating them. Exposure to these groups made them more equipped to handle their individual needs, both biomedical and emotional. They created community-based health outreach, made the physician-patient dynamic more egalitarian, defended patient confidentiality, began to ask more culturally sensitive questions to provide more specialized outreach and began to take a more holistic approach to medicine to meet more of the patients’ needs. These amendments had a lasting impact on American health.

The third and last chapter of this study focused on the political challenges that impacted physicians working in New York City during the 1980’s. As discussed in depth during the second chapter, HIV/AIDS impacted specific groups of socially marginalized people, which transformed the epidemic into a highly charged political issue. AIDS politics arose within the hospital, at a city level, and at a national level. While some of the physicians did not pay
attention to the politics of AIDS, others actively sought out to address the political issues that arose from the epidemic. Some were even forced to confront the political action because AIDS activists came to the hospital itself. The politics of AIDS certainly presented unique challenges for those working in medicine. The professionals adapted by actively engaging, defying and amending hospital policies, filling the void left by late city and national governmental action through outreach, and participating in and responding to AIDS activism. The changes that emerged from such political engagement have had lasting effects on American medicine.

This thesis is very personal to me on multiple angles and has truly been a rewarding project of self-discovery, reconciling the histories of three very important facets of my identity: my family, the medical community, and the gay community. Now, as a gay-identified man attempting to enter into the medical profession, I find myself torn. A rough history has existed between the queer and medical communities, and still persists today with many gay physicians opting not to be out at work. I, myself, have been advised not to place my work with the gay community on my medical school application because of the conservative nature of medicine. At the same time, gay community members remain vigilant in critiquing western medicine, which viewed homosexual behavior as a pathology until the 1970’s, through queer theory and activism. This thesis has proven that these facets of my identity are not mutually exclusive. In addition, the thesis has educated me on my family’s history as physicians and citizens of New York.

As we look to the future, is crucial to examine such periods of struggle in medical history so that we can learn from them. Without discussion both the challenge and progress, history doomed to repeat itself. This is already happening as a new generation of young gay men, disconnected from the pain and fear that older generations felt while living through the early AIDS plague, is encountering disproportionate growth in HIV prevalence. This epidemic is still
raging on all over the world to this day, as there has yet to be an effective cure. This thesis is dedicated to those who have fallen victim to the human immunodeficiency virus both in the past and today as well as those who have fought it. It is my hope that this thesis humanized the ongoing epidemic for you, the reader, so that you may be vigilant in the ongoing transnational war against AIDS.


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Sanders, Keith. interview by author, December 27, 2013.


Zeale, Peter. interview by author, January 11, 2014.
Appendix I: Figures

Figure 1

How HIV invades a CD4 cell

Figure 2

Continuum of HIV Exposure and Infection
Figure 3
APPENDIX II: Physician Bios

Dr. Maria DeVita was born in Washington DC and raised in New Jersey. She attended Georgetown University, where she studied Biology and played on the varsity volleyball and basketball teams. From 1980-84, she continued her studies at Georgetown Medical School. After completing medical school, she moved on to her medical internship at Lenox Hill Hospital in Manhattan. Lenox Hill hospital is located in the Upper East Side neighborhood of Manhattan on 77th Street between Lexington Avenue and Park Avenue. She decided to remain at Lenox Hill for her residency and subsequently her nephrology fellowship. She currently works at Lenox Hill Hospital with her own private practice and teaching responsibilities, amounting to over thirty years being at Lenox Hill.

Dr. Michael DeVita grew up in New Jersey. He received his undergraduate degree in Psychology at Georgetown University, and then continued to earn his medical degree also at Georgetown, graduating in 1981. His internship in internal medicine at St. Vincent's Medical Center in Greenwich Village profoundly affected him and has been a major contributor to the physician he has become. He moved to Washington DC to complete his residency at Georgetown before returning to St. Vincent's for fellowship training in Critical Care in 1984. By this time, the AIDS epidemic was well described and the hospital was filling up with those patients. The last stop for many was the ICU where Dr. DeVita was learning and working. The medical, ethical, and social issues were confounding and disheartening, and yet this served as a springboard for him to become deeply involved in ethics, and palliative care. In 1988, he moved to the University of Pittsburgh where he rose to the rank of Professor of Critical Care and Internal Medicine. Among
his contributions to the literature, he and Dr. Dennis Greenbaum authored the first textbook chapter on the care of the AIDS patient in the ICU in the Textbook of Critical Care Medicine. Michael DeVita is currently a Critical Care and Palliative Care physician serving as Director of Critical Care Services at Harlem Hospital Center in New York.

**Dr. Dennis Greenbaum** was born and raised in Brooklyn, one of the five boroughs of New York City. He studied at Rutgers University in New Jersey and then moved on to attend medical school at Georgetown University, graduating in 1968. After graduating, he began completed an internship year and 1 year of residency at St. Vincent’s Hospital in the West Village of Manhattan. However, his residency was interrupted in 1970, as the Vietnam War raged and he entered the army for two years. When he returned from Vietnam in 1972, he finished his residency at St. Vincent’s and stayed there until the hospitals closure in 2010. At the onset of the epidemic in 1981, he had 9 years of experience as a licensed attending physician at the hospital.

St. Vincent’s hospital’s location in the West Village, then the gay neighborhood of New York City, had huge effects on his experience working there. Between 1981 and 1985, 1 out of every 6 patients diagnosed with HIV in the United States were diagnosed at St. Vincent’s hospital.\(^{148}\) Greenbaum eventually became the leader of the Intensive Care Unit, or ICU, where patients with life threatening conditions are admitted in the hospital. He now works in the Intensive Care Unit at Harlem Hospital.

\(^{148}\) Dennis Greenbaum, interview by author, December 18, 2013.
Dr. Craig Keyes grew up in Wisconsin in a small dairy farming town. I started his undergraduate studies at Columbia University in New York, but I transferred to the University of Wisconsin when his father got sick. Keyes graduated from the University of Wisconsin in 1978 with a triple major in molecular biology, forensic psychology and theatre. He took a gap year in New York City and eventually entered medical school in Wisconsin in 1979. However, he was in New York probably half the time he was in medical school because he completed most of his rotations at New York University, Mount Sinai and Columbia University. He graduated from the university of Wisconsin in 1983, when he returned to New York to begin his neuroradiology residency at Columbia University. As a member of the gay community living in the West Village, Keyes felt compelled to respond to the AIDS crisis. He switched to another residency at Lennox Hill Hospital, where he eventually ran the AIDS ward. In addition, he applied for and received a grant to run an STI and HIV clinic in the West Village. It was a community health project within the gay community services center in the West Village on West 13th Street between 7th and 8th avenue. After his brother died of AIDS in 1993, Keyes decided to work with health systems at large. He currently develops clinical programs for large populations with chronic illness such as HIV, serving as CEO and Global President of Alere Health.

Dr. Sharon Kiely grew up in Monmouth County, New Jersey, where she attended catholic grade school and high school. In 1975, she began nursing school at Georgetown University. After two years of nursing school, she switched her academic program to major in psychology and minor in biology, graduating two and a half years later in 1980. She attended Georgetown medical school from 1980-1984. At the end of medical school she only applied to
programs in New York City because her partner and future husband, Dr. Michael DeVita, had his fellowship there. She started at St. Vincent’s in July 1984, living in the West Village/Chelsea area on W 15 St. She attended the primary care residency program at St. Vincent’s which was part of the department of community medicine. She spent 6 months of the year engaging with at risk populations of the West Village, such as the homeless, and six months of the year in hospital. She remained at St. Vincent’s until July of 1988, when her family moved to Pittsburgh. She now serves as the Senior Vice President of Medical Affairs & Chief Medical Officer for Stamford Health System in Stamford, Connecticut.

Dr. Vincent Patalano II grew up in Boston, Massachusetts. He attended the University of Pennsylvania for one year before transferring to Harvard University in 1981. Patalano graduated with a degree in General studies, focusing on Psychology and social relations, in 1984. In 1985, he began medical school at Boston University. After graduating in 1988, he did a one year of an internal medicine internship at Cambridge Hospital in Boston. He then moved to New York, where he completed his residency at Manhattan Ear and Throat Hospital, which is on the Upper East Side of New York. He did three years of ophthalmology there, from 1989-1992. He now serves as Chief of Ophthalmology for Cambridge Health Alliance in Boston, Massachusetts.

Dr. Keith Sanders grew up in Atlanta, Georgia. He studied Biology at the University of Pennsylvania, graduating in 1983. Before medical school, he worked as a technician in one of the hospitals in downtown Atlanta, where he was first exposed to AIDS patients. He graduated from Emory University Medical School in 1987. He then moved on to spend an internship year doing internal medicine at Emory. In 1988, he moved to New York City, where he was a
neurology resident at Columbia University Medical Center until 1991. While in New York, Sanders worked at Columbia-Presbyterian Hospital on 168th Street and Harlem Hospital on 135th Street. Though the two hospitals were both far uptown, they had very different patronage. He now serves as the Chief Operating Officer of AcuteCare Telemedicine, Medical Director of the Stroke Center at Saint Joseph's Hospital, and President of Atlanta Neurology.

**Dr. Peter Zeale** grew up in Bronx, one of the five boroughs of New York City. He attended to Cardinal Spellman High School in the Bronx and then went to Manhattan College. After two years as an electrical engineering major, he switched over to biochemistry. He finished his undergraduate degree in 1975 and then went to Georgetown medical school in Washington D.C. from 1975 to 1979. After medical school, he returned to New York City to start his internship in July of 1979 at St. Vincent’s hospital and finished training there in June of 1983. Zeale then went into a private practice from 1983, starting his own internal medicine private practice on 7th Street in the Greenwich Village/Chelsea area of Manhattan, which is where he remains today.
Appendix III: Interview Transcripts

Dr. Maria DeVita – Interviewed January 25, 2014

Briefly describe your background before 1980:
I was born in Washington, DC, actually and moved to NJ when I was three with the family. I am one of seven children and am the only girl with six brothers. Growing up, we were the typical Italian family I guess, lots of kids, we hung out in the neighborhood a lot. I was very athletic; I did all the sports things. My father always had a rule that was if one of the DeVita children wanted to do something then all of the DeVita children had to do it. So my younger siblings and myself were always included in all the kid’s activities, so that was a lot of fun. Then, in terms of kick the can or baseball or football or capture the flag. I went to Province (?) High School which was the local public high school. I was in the band and did sports. Then I went to Georgetown University as an undeclared major and then became a bio major. I played volleyball and basketball there. Then from 1980-84 I went to Georgetown Medical School. Then I finished medical school and did my medical internship at Lenox Hill Hospital in Manhattan and I stayed there for my residency and subsequently stayed at Lenox Hill Hospital for my nephology fellowship and then I stayed at Lenox Hill Hospital for private practice and teaching responsibilities; so it’s been thirty years being at the one place. It’s been pretty amazing.

Where is Lenox Hill Hospital located?
Lenox Hill is located on the Upper East Side of Manhattan; 77th and Lexington between Lexington and Park.

Before you moved to New York, were there any aspects of your upbringing that would affect your approach to gay patients, IV drug users, or hemophiliacs?
Not that I would recall. I didn’t have much exposure to any of those things. I was pretty naïve as a kid actually. I was very athletic and a lot of my coaches were lesbian, which I learned retrospectively; now it seems pretty obvious. Otherwise, no. I wasn’t swayed pro or against. I didn’t actually have any thoughts about it.

What prompted you to enter medicine?
Both my parents are physicians, and I liked sciences, and I thought it would be an exciting field.

Could you go a little bit more in depth of what you were doing at Lenox Hill?
I went there as a medical intern, so I was in general medical service. Any medical admission. We would have rotations on what we called the general medical floor. We had rotations in the intensive care unit; we had a rotation in the critical care unit. Basically you would see patients that were admitted to the hospital for any diagnosis – it could be pneumonia, small bowel obstructions, fevers, cancers, what not, and we would take care of them in association. We had a team of two interns and a resident – interns are first year postgraduates and residents are second or third year postgraduates and we would also have an attending supervising us, and you would change rotations every calendar month. And then I stayed on as a resident; resident was more or less the same except you were responsible for the interns and you had a chance to do some electives. The electives could be any subspecialty of internal medicine – so they could be cardiac care, renal care, human oncologic, gastrointestinal, what not. So that was two years of
just standard procedure in terms of residency training. During my residency I really enjoyed working with some of the nephrologists at Lenox Hill Hospital in terms of fluid and life light balance, and blood pressure treatments, and kidney disease, so I decided to do a fellowship in nephrology. I was going to leave Lenox Hill but I wanted to stay in Manhattan so subsequently I decided to stay in Lenox Hill because I liked the team that was there already.

Did you hear AIDS being talked about in medical school?
AIDS? No. But I remember as a third or fourth year, 1983-84, I was definitely in the medical ICU and we had two patients with the HTLV3, which was the virus that it was called. Both these patients happened to be Haitian and that’s when I first heard of this HTLV3. I hadn’t heard of AIDS until I was definitely an intern or a resident, even, maybe. It was just HTLV3, and basically they called it the four H’s: hemophiliacs, homosexual, Haitian, heroine maybe, for IV drug abuse. So I learned that as a medical student and it was just during that rotation as a medical student those two years, and I don’t recall having any formal lectures or discussions about it. Georgetown didn’t expand upon it there. Then I went to New York, and somewhere up there it became AIDS. I don’t recall the transition. The second half of my senior year, by 1986, it was a full-blown epidemic. We even had a floor, called the AIDS floor; they reconfigured the hospital to have all the patients cared for in the same unit. That was what I remember.

Do you remember how people talked about HTLV3 when you saw it at Georgetown?
I remember the patient; I can sort of remember the floor and his room. It wasn’t a big deal. Maybe I just didn’t have good exposure to it or maybe I have a bad memory but it was just this thing that it was HTLV3, it was those four categories, then you get really sick and you die. It was one of these things because we didn’t know anything about it. It was more of a naïve thing, we didn’t know anything. It had just come out that it was the virus, that it was HTLV3, they finally had figured that part out. That’s it that was my only exposure in medical school.

Did they approach it differently when you were in New York because they had more exposure to it?
By the time I got exposed to it, I was on rotations where I wasn’t so involved (1983-84). Definitely before that I didn’t have any exposure. I don’t recall any exposure. I maybe had heard of it but I didn’t learn about it in lecture class or anything. I don’t recall that. Then the third year definitely, but you’re not so involved with stuff. My fourth year I was away in Southeast Asia for two months, so then when I came back I was on some electives. I don’t have any formal lectures. By the time I’m first hearing about this was six months before I graduate, around early 1984. It was just the ICU rotation where they’re talking about HTLV3. But I definitely did not have any formal lectures on it. There weren’t many discussions; we just went on it in rounds. Like I said there were those four categories, and we didn’t know much about it, and my recollection was like we just changed rotations like I was doing some elective, like I was doing orthopedics, or something where I wasn’t really exposed to it. In distinction when you got up to Manhattan, there was a lot to do about it. You would hear about it. We started this wing, and majorities of patients at Lenox Hill hospital were homosexual. I don’t know if I had any other thoughts about it I just thought that if you were gay you could get it. We had a lot of Haitians and a few hemophiliacs, but 90% of the patients were gay.

There weren’t a lot of IV drug users in the hospital?
Majority gay, definitely a few drug abusers – I forgot about them. Definitely a few drug abusers. Percentage wise I can’t give you a number. People with multiple transfusions – I definitely had a couple patients who had AIDS from transfusions as well. And again it was just that category; the biggest thing I remember was when you do a rotation on that wing – the aids floor – was just how sick they were. A majority of the patients were definitely gay. They were almost quarantined at the time; it was sort of an interesting thing. And I experienced them more as electives; they didn’t have a set rotation there. I forget how the floor was covered.

I could take more about the AIDS floor, everyone was in a private room. You had to wear a mask or gloves. I still think they were trying to figure out how the virus was contracted and how it was spread. Most of the patients had pneumonitis, pneumonia, and were just short of breadth the whole time and had really high fevers. There was definitely cachexia (?), a lot of weight loss, and almost looked like prisoners of war. Lost all their muscle mass and were very cachectic. It was very tragic, they all just looked awful. A lot of them got cryptosporidium, which was ongoing diarrhea, worse than cholera diarrhea, so they would just be wasting away. Again, there was no treatment for them, you would just sort of treat them with different – you would give them (something) for the pneumocystis pneumonia, you would give them some sort of anti-diarrheal medicine for the cryptosporidium, and most of the time they would just continue to (something 12:33) and then they would pass away. And I think few people would, well I don’t even know if anyone left the hospital, I would say that a minority of people left the hospital. The Kaposi’s was there, I don’t think it was actively treated but people were covered with Kaposi’s. I’m sure you’ve seen the movie Philadelphia. Everybody had purple stuff all of them. It was like the measles, they had multiple lesions.

**Do you remember when they set up the floor or got rid of it?**
They set up the floor probably in, this is speculation, maybe 1985. And then maybe it went through, I’m guessing here, to 1990. Craig would know, he ran the floor for a while. I’ll let him speak for himself. It was five or six years I guess. And then it was antiretrovirals got invented and we were giving them and – one of the reasons it got instituted was because it was a New York state law. **About what?** New York state required, I don’t know if it was the law or if it was the hospital, whatever, they were mandated to have an aids specific area of the hospital.

**Was that meant for quarantine or is that meant for, because there were so many patients that you...**
I think it was because there were so many patients. Again I’m a little naïve there, I just thought it was just – they said look we have to have, to get our hands around this, better get our head around it, better see what’s going on here, and it’s better just to treat those patients in a similar setting. Like, I never thought it was communicable, you know, so like when I was on the floor log, because everyone had electrolyte abnormalities, I was a nephrology fellow, and I was a nephrology attendant during part of it, so I would always go in there, I wasn’t like oh my gosh I’m going to get sick, it was sort of just sad. It was just really sad. That was like my only thought process the whole time, it was just really sad.

**You talked about personal risked. Were you not concerned with personal risk at all when treating AIDS patients – do you remember how that compared to other doctors?**
I think there were doctors that were definitely afraid that it was some sort of communicable illness and that they could contract it to some degree. I never felt that way. Having said that, I was pretty thrilled with Craig, and Craig was gay and we would do stuff with him – you know he had a house up in New York state and Keith and I would go visit him there with him and his boyfriend, so we were sort of, I sort of was never of the mindset to be concerned about that I guess. I don’t know if that was my nature or if I was just friendly with Craig and Craig didn’t have any fears about it and he was sort of overwhelmed even at the time about – some of his friends would come in and his brother was sick so I indirectly identified with him. I said well if Craig can do it than I can do it. And then I think it was pretty well established, you know, how you could contract it by that point, you know, those four categories. My only thought process outside that normal range is that most of the men that contracted it were very promiscuous, and I found that like astounding. No, like some of these men would have had multiple partners and not knowing their names. I wasn’t really offended by the whole thing, I thought it was sort of sad, but I was sort of shocked by the promiscuity. But again I think I was pretty naive, maybe many people are pretty promiscuous. But some of these guys would say, “oh yeah you know I might have 100 partners in a month,” which I found really astounding. And again I don’t know if that was New York City, I don’t know if that was the gay culture at the time, I certainly know it’s not the gay culture now. But I think New York City at that time, my exposure was that most of the gay man who had AIDS were very promiscuous. And I would definitely say that some of my colleagues would say it was, you know, um, it was their just desserts to sort of get that – they got AIDS because they were just too promiscuous, and all this about revenge, satin, blah blah blah. I’m not very religious so I don’t get into all that stuff. It was a little over the top but it was rather said – but it was definitely one of the more promiscuous guys. There were a few guys that were actually very closeted, like even three guys that I worked with got AIDS and died… Were they doctors? No they were gay, but they weren’t openly gay, so I don’t know if they were just promiscuous or so, it’s a very biased comment but you know the people that were very quiet about their gayness also seemed to have it so I don’t know if they were promiscuous or not, so I was like “oh my god I didn’t even know he was gay.” And then all of a sudden he had AIDS and died.

So those were your medical workers who got sick as well?
So I have three medical co-workers that died.

So you mentioned there was a bit of religious kind of sentiment going on in the hospital – was that more widespread or, what proportion of people would think that way?
It was definitely not hospital wide. I think it was just a few people in the doctors lounge sort of making snide remarks type thing, but I definitely heard it more than once. I don’t think it was the prevalent thought process.

Going into the different groups that you were treating: was there any differences as to how you were treating them? Maybe it could be opportunistic infections or also maybe treating a drug user would be different than treating someone who got it from a transfusion or a gay patient.
My experience is a little skewed – I would say that overwhelmingly the patients were gay that I was treating in Manhattan at the time. I didn’t have any opinions on them, I think it was the rare person that got it from a transfusion. If anything, it would be, “you’re not gay?” type thing. And
then I didn’t even see too many Haitians. The HTLV3 Haitian guys were Georgetown – there must have been some Haitian people but I don’t remember them – it was, my recollection and experience was that it was mostly just gay men. So they were all there, and we just sort of treated them. It was said because they were all really tied, we gave them a ton of IV fluid – it was terrible. I’m sure the other physician must have said that too.

As a nephrologist, are there specific things that you would tend to care for or different things that you would see that maybe another type of doctor wouldn’t?
I think we would all see everything but I would be, basically, well most of the people with AIDS in the 1980’s would have renal failure, usually from the Bactrim because the Bactrim can be nephrotoxic, and they could have either high sodium levels or low sodium levels because of all the diarrhea they’re having from their cryptosporosis, cryptosporidium, and also potassium perturbations. The typical consult would be for some sort of electrolyte abnormality, and then dehydration, just helped guiding the fluids. So we would go in there and just sort of give them – just change it you know sometimes they were getting normal saline with some potassium, we would have to change it to ephnomal (??), we would just change the rates around. But that would be the day-to-day maintenance. It was renal failure and electrolyte abnormalities – it was very common. I mean if the wing had twenty beds, you know we were seeing like fifteen of them. It was just like everybody had a perturbation.

What were your greatest day-to-day challenges in treating the AIDS patients?
You had this sense of hopelessness actually, just going there and just saying “Gosh you know what am I doing,” it’s like you can’t fix this. So you felt really hopeless. And then talking to somebody who sort of knows their prognosis is awful - how do you have a conversation with someone like that? You know so you have to sort of come to grips with that. The patient gets hopeless, you’re job description is that you can’t be hopeless about it. So I think the biggest challenge was sort of like “all that jazz,” you have to go showtime. You have to go in there and sort of make the best of it in a very grim situation. I think somebody with terminal cancer, they need the push or they sort of go on hospice or something like that, I think at the time, because these men were so young most of the time, there wasn’t any sort of sense of withdraw care yet, you sort of do everything until they just died. I mean we would maybe withdraw care at the bitter end. But they all came into the hospital, they were all sort of really sick. You just keep them going – but some people would spend like a month in the hospital and then just go home and die. So it was really tragic. So I think the medical stuff was easy, although I couldn’t fix the underlying diagnosis, that part was difficult, we couldn’t do – what I had to do in terms of the kidney stuff and the electrolyte stuff was pretty straightforward as far as my training goes. So it was the other emotional components of it and the, almost the futility of it all that was difficult to deal with. The patients and then our interaction with the patients, and then your own little feelings about it. So it was hard, it was definitely an effort to sort of go in there and see all those patients.

Did it get easier or harder as time went on?
No I would say it got harder, I’m not good at disassociating, just going there and doing it and leave. I’m sort of pretty attached to my patients; sort of wear my heart on my sleeve type thing, so I always found it very exhausting. But you know it’s just what I did, you try to make the best of it and then you sort of just moved on with everything – but it was definitely, I mean I guess
you can have some sort of compartmentalization of it, but I think as you got to know people and you have connections, social connections with that person, and then friends of the people would come it, so it definitely had an emotional toll – I mean it wears you down. You know it’s not good to keep taking care of people if they’re all going to die. It’s really sad.

Now the epidemic is 30 years ago, that part of it at least. When you think back to that time, is there any specific thoughts or stories that come to mind when you think of AIDS?

Not really actually. It was a terrible time, I don’t think about it a lot. It was just nice that it ended. I remember when they closed down the aids wards because they didn’t need it anymore, that was like, victory. And you just said oh my god I’m so happy that’s over, it’s almost like you went through the war. You’re happy that it’s over, that there’s resolution that these guys weren’t dying anymore. And I think a lot of things happened. Anti-retiral virals came around, there was a big push for condom use, to not be so promiscuous so the community, and in particular the gay community, really attacked it on all fronts. Really trying to get government, as you know, all that NIH stuff – so they really pushed for better dollars for research, but they also, within their own community, took charge and said hey, you know, we have to change our behavior, we have to be more careful about this, and so my recollection was that it was really a grassroots effort from the gay community to really change it. I mean I think it got cured, not cured, but treated because the people who were affected by it really had the wear with all to sort of mount a fight against it. I don’t know what really triggered that, I don’t know if it was all gays or a certain number of gays or whatever, but you don’t see that with many other illnesses. You know have your breast cancer walks and this and that for other illnesses, but the AIDS was really a force and everybody was involved with it. So I remember that, like “oh my gosh, they really changed everything.” I was really happy I didn’t have to go into the 8 east anymore.

So what were the hardest moments as a doctor in NYC during the epidemic?

I think I sort of already said it. It was the emotional component of having the sense that 98% of the people were not going to survive and if they did they were just going to be back and not survive. Most of them had their own support systems, but a few of them would ask, “am I going to survive or not survive?” and the answer was always, “no, but you’re not going to die right now.” So I deal with a lot of life and death now with my kidney stuff, but I was thrown into that much earlier than I expected; dealing with life and death.

Do you feel like your perspective as a doctor in NYC is different from your colleagues in other parts of the nation?

I would say yeah. New York and San Francisco had the two largest gay communities. They were the two cities that were really effected the most by the AIDS epidemic. I had friends that didn’t even have AIDS patients. They were in some communities where those categories weren’t there, so they didn’t see it. I had a huge exposure to aids and some of my colleagues didn’t have any.

If you weren’t in medicine, you wouldn’t have exposure. If you were an orthopedic surgeon in Cincinnati, you wouldn’t even see anything aids related. So I think that my education was definitely skewed having been a physician in Manhattan and medicine at that time.

How did the epidemic shape your view of western medicine, both research and in the hospital?
During the time I think I was just too naïve to realize the bigger picture. That’s why I always admired Craig. He said, “I’m going to change this,” and I would just be like, “What are you talking about?” I didn’t have the wherewithal to comprehend that you could even do that. For me the biggest thing was that if you put your mind to it, you could probably get things changed, but it takes a lot of time and effort. The fact that they could rally and get those government dollars to do research to come up with these drugs… I think also the pharmaceutical companies saw that there was opportunities here and they got involved in it. It wasn’t all NIH research, it was probably private industry research as well. They were able to come together to do it.

Did you ever fear you would contract AIDS or spread it to your patients?
No. I don’t know why – maybe I was naïve. I figured I wasn’t a drug abuser. I mean how would I get it? I maybe thought I could get it in the air, but back then you had to wear a mask. I never thought that I would get AIDS, but having said that my cuticles crack a lot so I had a lot of open sites on my fingers some times. I would definitely wear gloves because I didn’t want to get an exposure, but I would do the same for hepatitis or something else. I don’t think I was overly freaked out by it. I definitely was not looking to have romantic interludes with a bisexual man though.

How do you think that the discovery of HIV affected treatment of AIDS?
I think that was before my time. They isolated the virus, but once you isolate the virus you have to do all the virology.

To many the public announcement that Rock Hudson and Magic Johnson brought the epidemic to the forefront? How did you perceive the effects of the announcements?
That’s sort of interesting – I guess I was kind of naïve to that. You think they brought it to the forefront? I could see how that could be true because they were notable public figures. I think from my view of it, we were already immersed in it and they were already doing a lot of research. New York City was really ground 0 for AIDS at the time. NYC was doing a ton of stuff, so I feel like I was already in the midst of it all. For the average person who wasn’t in Manhattan at the time, they could have put a name and a face to it. I sort of missed that because I was already immersed in it. He was a good spokesman. Had it been Rodman, I doubt people would have cared, but Magic Johnson was personable and a good speaker.

How did the approval of AZT as the first ARV drug by the FDA affect AIDS treatment?
Oh my God, it was like a miracle. All of a sudden you would give people a pill and they would live. It was really amazing. I can imagine when they found the cure for polio or TB – It really changed everything. I had never been in something as dramatic as that. It was like when penicillin was invented. It was amazing.

So you saw it as a positive thing?
Well I couldn’t even list the side effects for you now, but yeah. These people were dying and now they weren’t dying. It was side effects and live or else you’re dead.

AZT was the most expensive pharmaceutical drug at the time. Did you or your patients have issues with affordability?
I don’t recall. I was just a consultant for these patients, so I wasn’t involved in getting the drug. I’m not sure if I ever even prescribed the drug individually.

**Are you aware of buyers clubs?**
I don’t recall it, and I think in medicine when you’re desperate you’ll do anything and I don’t have any problem with that.

There are a couple of things now where people seek alternate means to get medications. The FDA I think tries to protect people. There’s also a liability issue that they want to make sure the government doesn’t get sued, so they are very strict. I think they do miss a few opportunities, but I understand where they’re coming from. I don’t have a strong opinion on it. If people can get their hands on something effective….but that’s true now. There are a lot of drugs outside of the US that are not approved in the United States. I’m ok with that. I don’t have a big opinion, but that thought process I’m ok with.

**Have you heard of ACT UP?**
Oh yeah

**What was your reaction to ACT UP?**
I think I’m pretty boring. I think that they wanted to draw attention to a big plight, and I thought that that was good. I think that now homosexuality isn’t so negatively portrayed. So my kids know many gay people and there’s no stigma attached. When I was growing up, I didn’t know any gay people that were openly gay. When I went to college I knew that some kids retrospectively were gay. I didn’t know many openly gay guys in college. Craig was actually the first gay guy I knew, and then all of his friends. And I sort of knew there were other gay men within my training. The point of that is that they were able to speak their mind and change policy. I think that was a good thing. And to make any social change I think you have to be really loud and – well not belligerent, but you have to have a voice. Everything they did was for that attention, and I think that was fine. I didn’t have any negative feeling about it.

**Did others have negative opinions?**
I think even now I know people who don’t have – At the time I was aware of people who thought that AIDS was a kind of retribution – that the people were just acting up inappropriately. That’s just because they didn’t support the gay rights movement either.

**Could you go more in depth about the gay community action?**
I don’t think I can elaborate much more.

**What were your thoughts on the CDC, FDA, and NIH’s responses?**
I don’t know what their responses were. Maybe they were slow to respond. I don’t have an opinion – maybe I was in the dark.

**How about the Reagan administration?**
I have no idea. Haha.
How would you respond to activist criticism that medical professionals didn’t relay the urgency of the epidemic to the national agencies?
Again, I’m pretty ignorant there. Maybe they didn’t alarm the sirens, but we had a whole AIDS floor. I guess that people thought it was just futile. Maybe we were late to come to the table. I can see where people could say that. Its like that for every illness – there’s an uproar, like “why haven’t they cured Parkinson’s? Why haven’t they cured breast cancer, or this and that?” I think that there will always be a backlash of why didn’t we do more. I think that that’s a generic human failing. I think that they should spend a lot more money on health care – it should be expensive.

How would you respond to activist criticism that the medical community was racist, homophobic, classist, and sexist in the clinical trials and hospital setting?
The clinical trials I don’t know.
In the hospital setting, yeah I think that people were homophobic, but I think it was homophobic by default. I think that people were just scared of the illness, and the illness was in gay people. I think that if that illness happened to another population that they would have been phobic for those people too. I don’t think it was homophobia, it was just that people didn’t want AIDS, which was in the gay community.

How do you feel working on AIDS patients in the 1980’s has affected your career?
I mean you can see the transition from before and after. You tell stories of the experience I went through. I don’t have any strong feeling on this one because it really didn’t change the direction of my life.

I was happy when the epidemic ended. I still treat a lot of patients with HIV disease, but that’s really common in medicine now, to have a lot of people with HIV. In that regard, I can reminisce and say its nice to treat HIV as a chronic illness and not as a death sentence. Its clearly a chronic disease now, and people live long, productive lives. So that’s nice. I guess in that regard it’s nice to see the transition. I don’t have any big scars.

How do you feel the AIDS epidemic affected the medical community as a whole?
I think that people saw that if a community rose around an issue, we can have better solutions. I think that’s important.

It also made the medical community more aware of the need to contain infectious diseases. So they you have to wear gowns and masks and gloves for certain things in general just to make sure it doesn’t spread from person to person. Its not just AIDS per se, but these universal precautions now exist because of the AIDS epidemic. It was sort of interesting and came about during AIDS that if someone has TB, you can say they have TB, but if someone had AIDS, you couldn’t say they had AIDS, so medically this became universal precautions. Because you couldn’t tease out who had AIDS and who didn’t have AIDS and what was communicable or not, you had to treat everybody as if they were possibly infected. That still goes on in medicine, so I think that was a big difference. I don’t know if it’s a plus or minus, but that’s one of the things that came out of it - these universal precautions. You treat everybody equally as if they had some communicable illness.
Dr. Michael DeVita – Interviewed November 1, 2013 and November 3, 2013

Did you have experiences with gay or IV drug users before the epidemic?
Both my parents were doctors so we had a lot of tolerance because of the real life problems that people have. Mother often talked about medicine at dinner. I was at Georgetown as an undergrad and took bioethics as a course, where I learned the various principles of ethics, which I think had an impact on me. I met Father King, a Jesuit that had a very liberal stance. [Homosexuality and IV drug use] didn’t matter to me; I didn’t think about it. When I went to St. Vincent’s, it was right in front of me all the time and it never mattered to me. It never mattered; I knew that it happened but I never ran into it.

Why did you choose to enter medicine?
I loved science. I enjoyed the thoughtfulness of it. The last thing I wanted to do when I got to college was be a doctor because of my parents. Their private life was a disaster and I thought that this was due to them being doctors. I thought that being a doctor had too great demands on a personal level. I didn’t want my job to interfere with my life. I was a Psychology major as I completed my junior year of college and my parents suggested that I be a Psychiatrist over a psychologist because I would get better pay, better job security, and I could prescribe drugs. Its just a better life to them. As a senior I took anatomy and psychology, I really liked it and decided to go to Medical school. Once I got there I really loved it. I loved the science and the caring components of the medical field.

Describe work in NYC during the 1980s
In 1981 I went there as an intern working in internal medicine. I was working in the ICU and ER taking care of patients who were admitted with all sorts of diseases. In all settings I cam across the diverse background of Greenwich Village. There were a lot of Italians – it was an Italian neighborhood. It was a gay neighborhood and a drug addict and alcoholic neighborhood too. People of all these flavors came into the hospital. Sometimes I was caring for people who were old; other times I was caring for young people who had damaged themselves.

First Thoughts in the hospital
I was definitely in the thick of it, but it was part of the job I was there to do. With alcoholics I helped them not get DT’s and treated their liver disease, kidney disease and seizures. The gay men there was a thing that they called “gay bowel disease/syndrome” that was a wasting syndrome. People came in with bad diarrhea. They would come in and were wasting away to nothing. They also had Kaposi Sarcoma.

Please discuss
Gay Bowel Disease was an unofficial name that people called AIDS. That’s what they called it at the time. The diarrhea was caused from a bunch of things, but one of them was cryptosporidium.

Describe first time you heard AIDS discussed
GRID was much later, like 1982 or 83. Gay related immune deficiency. First the people had gay bowel disease and then KS. When they found out it was due to cryptosporidium, a bacteria that grows only in people that are severely immune compromised, that’s when they started looking at
T cells and what was going on with T cells. I never heard about it in medical school. We didn’t talk about it, we saw it and people said this is what its called. Only gays had this. Remember this was in NYC where it started. There weren’t a lot of people. There were just a couple. The first report was in 1980 with just 7 patients. It was a really rare disease at that point. We didn’t know there were opportunistic infections. They had diarrhea that we couldn’t diagnose, then they had pneumonia that we couldn’t diagnose then they had skin lesions that turned out to be KS that was so rare that people couldn’t believe it or the diagnosis wasn’t correct. I don’t know what people were saying. It was like, “isn’t this weird?”

Nobody knew whether it was from a toxin, bacteria or virus. Back then people did poppers a lot – they thought it was due to the poppers. Some people thought it was due to the gay lifestyle. One guy heard it called WOG – Wrath of God. That was used in the hospital. I heard one guy saying that he had heard that name. St. Vincent’s was a very respectful place. It was Catholic, but respectful trumped Catholic. It was thought of as a mission district hospital. Half the physicians there were gay, but the nuns there were really special. They would be walking around helping all the time and they were the most tolerant, wonderful people. They would have been excommunicated if they were found promoting condoms and stuff, but they did it because they knew it was the safest thing they could do for the people. They cared more about the people they were working with. It was their mission to try to save lives – it was not their mission to try to get people to convert.

**Talk about the names of the Disease**

It was called a bunch of things. One guy said he heard it called Wrath of God. He was just saying it. He was an oncologist so he actually had seen people with KS. He didn’t mean anything by it. We were not just hanging out chatting about the problem. We were just taking care of patients. It was before the epidemic. There was no reaction. Its obvious why the name came about – no one was pushing it. It made sense I guess – God killing the gays –its ridiculous but I heard it said once.

**Talk about your first interaction with an AIDS patient**

I do remember when I was in the ICU I had a patient with pneumocystis and I had to call the CDC to report it and the CDC flew a medicine to JFK and I had to call for someone in the hospital to pick up the drug, which was called pantamadine and bring it to the hospital. The patient died. It was that rare and that weird that we had to call the CDC to get the drug, which wasn’t released. We had it special on a compassionate use protocol. That told me that the govt and CDC knew about it and had done enough investigation on it to know what the treatment should be. It was in 1981. I think I took care of 2 or 3 patients that year that had AIDS, though it wasn’t called that then. People came in with KS more frequently, but it wasn’t a killer so we didn’t do much for that. We were treating diarrhea for the most part.

**What about when you returned in 1984?**

The hospital, instead of having a couple of people here and there, was filled with people who had AIDS. Out of 710 beds there were 100 patients with AIDS. We started testing people for HIV in 84 and 85.

**What was your concern w/ personal risk?**
I was pretty concerned. I was putting lines into patients and intubating them. If their blood got on me or my mucus membrane I was in big trouble. You had to be careful. Once we knew it was a retroviral infection we had to be careful with blood.

**Did that match the concern of your coworkers?**
Everybody was concerned. There were some people that were so concerned that they wouldn’t even go into the patients rooms. So there were some people who were very very worried, and there were people who just didn’t care. Joyce thought it was immoral to wear gloves and masks and gowns because people were dying. They needed humanity and not sterility. Most people took proper precautions, but cared for patients. Gowns and gloves are no big thing in a hospital. It was rare for people to refuse caring for AIDS patients, and when that happened the other doctors were upset. The hospital actually made a policy that you couldn’t refuse to care for patients. You would be fired for doing so. This came about because it was a Catholic hospital and they wanted to take care of people. The policy came about in the midst of aids as soon as they found out about it. There was a bit of discussion, but they stopped it.

**Infected workers?**
I knew a lot of medical professionals that were infected, but they were all gay. I didn’t know anyone that got sick from caring for patients.

**How did the Hippocratic oath inform your treatment?**
To me, the Hippocratic oath was irrelevant in caring for patients, but when people were deciding what to do at the hospital with some doctors refusing care of AIDS patients, the oath was often quoted as a reason to do it. The policy was based on the Hippocratic oath.

**What were your day to day challenges treating AIDS patients?**
I was in the ICU so everyone that came into the ICU with AIDS died. That was a challenge. We were actually more focused on getting people that didn’t want to be treated in the ICU on a ventilator off of a ventilator. I wrote an article on doing that. Its in Medical Clinics of North America. The tone of the paper will let you know what we were thinking.

**What were the hardest moments?**
We wouldn’t sleep. We were trying to make room for the patients because the hospital was being flooded with patients with AIDS who were going to die. We were campaigning/ trying to get the patients taken care of in a way that wouldn’t require them to be in the hospital. We wanted them to be able to stay in a nursing home or their own home because there wasn’t much we could do for them in the hospital. Day to day challenges were trying to manage beds and trying to deal with the horror of so many young people dying and trying to stay safe.

**What did you do to protect yourself?**
I just washed my hands carefully and wore a mask when I did a procedure that required me to get into blood or secretions.

There was quite a scare. When I tried to move to Pittsburgh in 1988 they tried to not hire me unless I got an AIDS test. I fought it, I said that’s illegal. and they said that they would hire me but wouldn’t insure me against AIDS. I said its fine by me because I didn’t know I had aids. I

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fought it all the way to the top and actually got the university to change their policy. They told me they were doing the test for employee records, but that they weren’t going to deny me a job for aids. I said I don’t care, its illegal for them to require an HIV test as a basis for employment.

AIDS scare/stigma within the medical community?
In Pittsburgh there was a huge paranoia. I had cared for more patients with AIDS in the ICU of St. Vincent’s than there were AIDS patients in all of Allegheny county when I moved there?

Greatest Challenges in NYC in the epidemic?
A lot of them hadn’t told their parents that they were gay let alone sick. It made it tough. We would be dealing with all sorts of stuff.

Did it get in way of job?
It was hard because you want to be honest and people have the right to not present their sexual affinities. Normally it wouldn’t be an issue. I mean, I was not telling families that their children were gay for years – that wasn’t the issue. The problem was that now their sons were dying and families wanted to know why their sons were dying and if you say he’s dying of AIDS, they know he’s gay. If you say he’s dying of pneumocystis, they know he’s gay, and it became an issue. So we had to talk to the patients to help them sort out their relationships with their families.

Was this different from other fatal diagnoses?
We still do this. Around death patients tend to be careful – they don’t want the information to get out. Meanwhile, their parents want to understand what’s going on so they can help their loved ones.

Were the families/patients receptive to you talking to them about their disclosure
Most parents were receptive because they loved their kids, but it was difficult for a lot of them because these kids left home because their fathers were abusing/making fun of them. You know – “you’re a girly man, you’re not a manly man”. So they left. And now you’re trying to get them to sort it out. It was very difficult.

How did the AIDS epidemic shape your perceptive of western medicine
It didn’t

How did AIDS allow you to see misogyny, racism and homophobia in medicine?
I believe that misogyny, racism, and homophobia was happening in medicine, but I didn’t have a part in it. I did not see it personally, so I didn’t have much to do. I feel like it came around. I feel like people like Dr. Gallo were working really hard to try to cure this disease. It didn’t bother me that they weren’t enrolling certain groups of people because it didn’t matter – they were still going to cure the disease just as fast. It wasn’t that important to me.

Talk about the homogeny of the clinical trials?
They didn’t know anything. The more heterogeneity in the study, the more difficult it is to figure out what’s happening. The best way to do studies like this is to have a very homogeneous population. The population they chose [gay white males] would be the largest one. Women with
AIDS were outnumbered 10 to 1. It was the gay men’s disease. Black men came in later – it was Haitians.

**Did you hear notions of quarantine?**
They were definitely quarantining AIDS patients. One we knew it was transmissible via blood and secretions, they were careful about putting patients in isolation. That is very common in medicine though – it goes back to year zero. AIDS patients were kept in a separate room. I don’t know anything about quarantining at a national scale.

**How did fear of transmission affect your time with patients**
I was just careful. I took the proper precautions. I did not worry about moving from an AIDS patient to another patient because I was so careful.

**How did discovery of HIV impact treatment?**
It didn’t back in those days because we didn’t have a treatment yet. We then knew it was a virus, but that didn’t change how we managed them in the intensive care unit. They were dying of bacterial and protozoan disease. After the discovery, they took extra careful precautions. They isolated the patients and medical professionals were required to wear gown and gloves. It was standard practice.

**What was the impact of Rock Hudson having AIDS?**
There were a number of people who came out of the closet with AIDS. He was the first big star, so I’m sure that probably made a difference for some. However, I was in Greenwich Village, so gay was just gay. It wasn’t as big of a deal or as surprising of a thing. I mean it was all that anyone would talk about in our community – about how everyone was dying. The entire town was dying. In NYC it was already in the forefront. In terms of popular culture, it was probably very important. I remember it being all over the news. It read, “Rock Hudson has AIDS.”
It was gay people and gay bashing was a huge college sport back then. The fact that a gay person was dying was like “Great! One less!” I mean, people just did not care. In the Village people were different.
Rock Hudson changed how it was financed. Its tough to hate a person who you had just admired for the past couple of years. It personalized and humanized the disease. If you’re in Kansas, you didn’t know anyone who was gay except maybe the “weird” kid down the block. You didn’t care about him. When rock Hudson and then Magic Johnson got it AIDS was suddenly a big deal because everyone admired them. There were more resources. Research wise, Ronald Reagan allocated lots of money to AIDS research. Rock Hudson didn’t cause it, but I’m sure that it helped. It improved the political milieu.

**Can you talk about needle safety precautions and needle share programs?**
There always were needle precautions, of course: who would want to be stuck with a needle. But now, sticking yourself with a needle was a potential death sentence. Furthermore, saliva, blood, urine, stool were potential death sentences if you became contaminated.

Joyce Wallace was a leader nationally and locally in promoting needle exchanges (and condom use). In both cases, Joyce argued that even our vices, however grievous, should not be a death sentence. She argued that ethically and morally we owed it to humanity the help to prevent death
from social vices, and hope later for the person to be ready to recover. This is a version of addiction is a health issue, not a moral or legal one. I think she had it right, and was decades ahead of the curve.

Can you talk more about what Joyce did?

Joyce Wallace was/is a primary care internist who worked in Greenwich Village in the 70's and 80's (I don't know about before or after that). She figured out early on that the disease was likely spread via blood or other body fluids and started collecting blood samples from prostitutes in the area. She figured that at some point, even though this was an undefined gay disease, if it was communicated through blood, that it would contaminate needles and cross into the heterosexual population. She thought that prostitutes may become an important vector for transmission. She collected the specimens, and the NIH became interested and gave her a grant to continue this work. Basically, she paid the prostitutes for their time, and then drew blood during that time. It went to NIH where it was frozen until testing became possible, and then it was all studied. She also received a grant from a condom manufacturer and distributed condoms to help promote safe sex.

Dr. Dennis Greenbaum – Interviewed December 18, 2013

Background before 1980

Well I come from Brooklyn, born and raised in Brooklyn. I went to college at Rutgers University and medical school at Georgetown. I graduated from Georgetown in 1968 and did my internship and residency at St. Vincent’s hospital. In the middle of that there was a little thing happening called the Vietnam War. Actually at that point it wasn’t called a war, it wasn’t called a war until several decades later. So I got into the army in 1970, after one year of medical internship and one year of residency. I got back [from Vietnam] in august of 1972 and completed my residency. I was there through the closure of the hospital in 2010. The AIDS epidemic began in 1981, so I had approximately 9 years as an attending physician after completion of my residency and my military responsibilities.

So that’s when it began. St Vincent’s as you can guess was the epicenter of the disease for a long time. Between 1981 and 1985, 1 out of every 6 patients diagnosed with HIV in the United States were diagnosed at St. Vincent’s hospital. We had one unit that was filled with aids patients – it had 36 beds. We had lots of experience.

Looking back, what are your thoughts on the epidemic?

Well there were millions of stories. A lot of those who died were working at St. Vincent’s hospital. We were in the West Village, which was not only a place where gay men lived, they sought work in that area so they would be close to home. We lost a lot of staff people and we lost a lot of neighbors. My next-door neighbors had four men in the apartment and they all died. Especially if you lived in that area and had a lot of contact in that area, you lost a lot of friends. There were a lot of memorial masses to go to. It was a time that really nobody could ever imagine what was going to happen. Nobody even knew what it was caused by until many years later. There were all kinds of theories that various oils or things that people inhaled were responsible. It wasn’t until several years later that the virus was identified. So those were the most significant memories that I felt personally, but there were a lot of other things. If you think
back about what the whole world was dealing with there were a lot of other stories. If there was a gay man a court, he was obligated to be in a box and nobody could get close to that person so that person was on a continuous basis locked in. The restaurants in Greenwich Village were all closing. Nobody wanted to go to the village to have dinner. There were all kinds of ridiculous concepts and fears that were all based on the fact that nobody knew what it was. Once we realized it was a virus we knew there were certain types of prevention that could be done and once that happened then it didn’t make the situation safe, but at least it gave us a direction to go in. Were not finished with that direction; I mean you would like to see a vaccine and periodically people talk of the likelihood of vaccine coming out soon. We still have hopes that there will be a vaccine, but a lot of the other mechanisms, the plans of correction that prevent us from getting the virus have been successful. Combination drug therapy and the use of protective devices such as condoms have really run the number of people dying from aids very low.

In the mid 1980s we had an 8 bed ICU in the Department of Medicine at St. Vincent’s and we had an average of 6 patients of 8 beds belonging to AIDS patients. There was a lot of thought of identifying a concentrated hospital so that a hospital – I think they were talking about Cabrini hospital – could become New York City’s AIDS hospital. Then once a patient was reasonably stabilized the patients could be moved to one place because there was no room for any patients other than AIDS patients when the volume was so high. But then once we realized that certain forms of isolation were unnecessary, the fear went down, the volume of patients went down. Our residents weren’t applying to St. Vincent’s because they were afraid to come there because they were afraid they would die. Visitors wouldn’t show up. Patients with other conditions would elect to go to other hospitals. So from a financial standpoint it was very difficult for all hospitals. That was the reason for this potential plan for the patients to move to Cabrini, but that never was done because the volume of patients that were really that sick began to decrease and the causes of death decreased.

Once somebody had the diagnosis of whatever they called it then – Gay Related Immune Deficiency, GRID (And there were other names before it became HIV) – that patients with those conditions had a 94-96% mortality. We would make the diagnosis, they would come in through the emergency room, they would go to the operating room to get a biopsy of the lung and by the time they would go up to the ICU where the diagnosis would be made. Then we would treat them to the extent that we were able to treat them. We could treat the opportunistic infection, which was then pneumocystis corinii. So we could treat them for that, but we couldn’t do anything to the immune deficiency. Even with that particular treatment, most of the patients didn’t even survive their first episode of pneumocystis. Even with the treatment directly at the Opportunistic Infections, more than 94% died in the first treatment. So between that and some of the other issues that began to be found – for example it was identified that patients that if patients were put on steroids had a little bit better recovery, so that became part of the act and then a little bit more over time the various medications and then the more recent HAART antiretroviral therapy. Right now, the longevity of patients with HIV is essentially the same as anyone else. This is a good thing, but then it poses other problems. Some people now are not even concerned about using protection so in certain groups like young men, there is a rise in incidence of HIV because they’re just not paying attention. They see others with HIV are fine so they’re not taking the precautions.
How did upbringing affect gay & IV drug user patients?
Well I don’t think I had any specific issues in my childhood that would have put me one way or the other. The area that I grew up in was a very Jewish neighborhood. There were no gay people that I’m aware of. There was no drug abuse that I was aware of. I guess it was my coming to St. Vincent’s in 1968 that was my first exposure to gay men and the whole gay culture. After the patients were identified at St. Vincent’s, they were so sick that they ended up in the intensive care unit. So consequently as the disease began to move around the world, I would get called to give lectures all over the world about HIV. I would give lectures in Sydney, literally all over and they were all based on the experience in the ICU managing patients with HIV. So it is primarily my job at St. Vincent’s that made me familiar with the gay community, but even at that point I didn’t have real contact with drug users. As the disease progressed, even at St. Vincent’s the new cases weren’t really drug users – that was really later on, maybe in the 1990s.

Can you describe your medical experience at St. Vincent’s?
I was the head of the medical ICU from he mid 70s through 2001. In 2001 I became chairman of medicine then.

What were your basic responsibilities?
Eventually over time we had a group that consisted of 5 physicians- btw 4 of those 5 physicians are still together at Lennox Hill. I got out of that group when I became chairman of medicine, but they moved as a group when St. Vincent’s closed. The responsibilities were for everything that went on in the ICU. So we had 5 people and we were responsible for the 4 ICU’s. We were responsible for the medical ICU, surgical ICU, cardiac surgical ICU and then eventually the respiratory ICU. The only ICU we were not involved in was the pediatric ICU because we didn’t have experience with kids. In each of these units aside from the medical unit, one of our people was in charge of that area. So one doctor was in charge of the medical ICU, one in charge of the surgical ICU, etc. We were all internists and it was an unusual situation when internists ran the ICUs of all of these other units that came from other departments. So we were in charge of administration and direct patient care, making rounds and teaching residents. Then we got approval to offer a Fellowship program. I’m not sure what the year was when that fellowship began. Dr. DeVita was either our 2nd or 3rd fellow. He was an attending physician staying with us for a year after completion of his fellowship.

Can you talk about the first time experienced AIDS patient?
We had a patient who came in with severe anemia. He was in the ICU and we got a (COMP BILL?? 8:20) from hematology. Hematology did a bone marrow aspiration to find out why he was anemic. So we put the bone marrow specimen on the table in the nursing station and they wrote the order to the submit the bone marrow to the laboratory. So she took a specimen to the lab and the lab identified the organism cryptosporidium, which is rarely found in adults. There had to have been a recent article saying that a hospital in NYC found a couple patients with this unusual disease that also had cryptosporidiosis, which is usually found in farm animals. So we put it all together and made the diagnosis. Though we were the epicenter, we were not the first hospital to diagnose this illness. The first two hospitals – NYU and San Francisco General – but then once we started seeing it, it skyrocketed because of the location in Greenwich Village. So that’s how we made that diagnosis – we were aware of these other findings of cryptosporidium and this weird disease that no one understood and we took it forward and made a diagnosis.
What were your initial reactions?
It was part of the bigger picture. In the first couple of weeks, no one even knew if we could connect these cases in SF and NYC because only one of them reported cryptosporidiosis. As time went on cryptosporidiosis was being diagnosed. It appeared very quickly that the failure of the immune system was responsible for these illnesses. So that’s why the term opportunistic infection came about – they are infections that take the opportunity to invade an individual without a properly functioning immune system. So the basic immune system is the retroviral infection and the opportunistic condition, whether it is pneumocystis, cryptosporidium, or whatever it is, is the opportunistic infection. There are also non-infectious opportunistic conditions such as cancer, colon cancer and Kaposi Sarcoma. Those were found frequently – we don’t see much of any of these anymore. Now we see patients coming in with other conditions. The interesting thing is that the vast majority of patients in most hospitals that are HIV patients and hospitalized are not hospitalized for their HIV. What used to be something that nobody guessed would happen- now people with HIV were having cardiac surgery and other kinds of procedures and are living healthy lives.

Can you comment on gay men working at St. Vincent’s?
Well I don’t know what the proportion of the population of the work force of the population at St. Vincent’s were gay. I don’t know if anyone does. Why would you know if someone is gay? I know that there is a tendency for people to go to work places close to home and Greenwich village is a great place to live, so there were a lot of gay people there. I would guess that there are a lot of gay people in any hospital in New York City or California. But the impact on their coworkers was horrible because they were being lost. Here were coworkers who were dying – people who they worked with for years. So I think that most people, even back then had an open enough mind to not blame people for being gay. These were their friends, their whole experience.

How did this shape the response to the epidemic?
Ill give you a response and see if it matches the question. I think the response to the HIV epidemic was spearheaded by a group called the Gay Men’s health crisis (GMHC). The GMHC handled HIV in a way that other conditions rarely see. They took control of everything. They went to all government agencies. Even today, the payment for services rendered to patients with HIV is higher than it is for other conditions because they wanted to be sure that doctors would want to treat HIV patients. So they had a large lobbying component. They visited the men at home. They worked as social workers and like family to the gay men who didn’t have family. Some of them had moved from middle America to Greenwich village and here they were all dying. So the GMHC figured out ways of doing lots of things – fund raisers and helping to support research – so this community-based group unlike any other that I was ever aware of really took the disease by the horn. And they are clearly responsible for most if not all of the initial response to the epidemic, but they are still active and still support all of the services that HIV patient’s need.

Can you talk about in hospital response to gay patients?
Well I suspect that people in Middle America probably wouldn’t have the same connection with gays in their neighborhood like big cities would. Chicago is not a good example because they
have a large gay population and plenty of HIV there too, as with obviously some of the cities in California like San Francisco. If you’re part of a community that has gay people, you’re more likely to be comfortable and familiar with them and would be able to work very comfortably with them, where there may be, especially during a time where there is fear of catching a deadly infection, people who did not have this closeness may move away from that and try not to get close, and have a less positive attitude toward treating. I have no data to support that though.

**What was your concern with personal risk?**

Well everybody was concerned about catching it because nobody had any idea of what was causing it. Because it was only affecting one population in the early stages in the United States, then there was some thought – appropriately – that this was sexually transmitted. There were people - not at our hospital – who thought that this was the gay man’s punishment for being gay. So there were those kinds of thoughts, but since we didn’t know what was causing it we used extraordinary precautions when we went to see a patient - this was the doctors, the nurses, and everybody. We wore total body gowns – everything was covered. We wore goggles, we wore masks, we had covers over our heads, blue plastic full body garb, and gloves. That was the only way we went in to see those patients. Now we go in and shake hands with them with nothing covering us because we know what the condition is and you don’t get HIV from shaking hands. I mentioned before that when these guys went to court, they were put in this booth to be separated from the jurors and everyone else. There was no way to keep everyone else isolated, so they put the suspected HIV patient into that booth. There was a television show at that time called the 64 thousand dollar question. When they got up to a certain level – the 32 thousand or 64 thousand dollar question, they put the patient into an isolation booth. In theory the audience might yell the answer to him, so this isolation booth was then adapted by the courts to put the HIV patients in so they wouldn’t let the germ out.

**How did the hospital’s Catholic identity shape its response?**

The mission of the hospital, like many hospitals, was to provide care to the needy – especially those who can’t afford it. This fit our mission – not that they couldn’t afford it because we took all patients- but it was our mission to treat people who were sick. They were the sickest of the sick, so it fit our mission perfectly.

**Do you know of any professionals who got sick when treating?**

I know several that died of the disease, but I don’t know whether they were infected by their patients.

**What were your thoughts on buyers clubs?**

At this point, nobody knew what would help and what would not. They were doing what they could to help themselves. They were doing what they thought was best, so I can’t blame them for that. IF the patient was doing that it wasn’t illegal for them. Forgetting the legal aspects, these were people with a 94% risk of dying, so trying to experiment with potential therapies is not a surprising thing.

**What was your reaction to ACT UP?**

Not familiar with them
How did the AIDS Epidemic affect your view of medicine?

It's not just American medicine because they were able to identify the cause in both the US and France. I think they did a wonderful job figuring out what the cause was and subsequently finding more details about the virus and identify treatments for this particular type of virus. It was exactly the way to go, and as I’m sure you are aware, there are many variations and combinations of medications. They developed a system known as the HAART, Highly Active Anti Retroviral Therapy, that is so successful that now the longevity of a patient with HIV so long as the patient takes all of the standard precautions and continues their regimen as prescribed, the longevity is about the same as people without HIV.

How did discovery of HIV change treatment?

Well remember that before everyone had their own theory of what was causing the disease. The people who were most scientifically oriented did feel that it was an infectious agent from the beginning although other people thought it was related to certain medications or other types of drugs that gay men utilized to enhance sex and others thought it was due to certain types of gasses, but most of the people who are used to infections did think that this was going to be an infection. This made it very clear because it identified a specific virus, so all of those other theories just went away and now the entire focus was just getting more information about the virus to know how it was structured so that the specific treatments could be developed against it. Well, it did clarify that this was an organism and it was not yet clear, however, how it was transmitted. So people really did have to continue to utilize protective precautions which are in line with a mask, gloves, full garb when you went to visit these patients, which of course the patients didn’t like because they couldn’t even see who the doctors was. They saw him, but with a big mask over his face. So it is not comfortable. When you want to get your health taken care of, it’s nice to see the face of the people taking care of you. It also made the situation cumbersome for the staff who were treating the patients because it was not an easy way of walking in and shaking their hands and doing what doctors do in general with patients who are not infected. So while it gave us a lot of hope in the beginning, which continued throughout, it was not a time that we could stop using all of those precautions because we knew it was infectious. Also, the other thing is that the diseases that we saw were the opportunistic diseases. It wasn’t a disease, or at least back then, a disease that was directly caused by the virus. The theory then was, and this is true now although we know that the virus can be the direct cause of the disease, that the virus caused a deficiency in the immune system itself, but that something else caused the manifestations of the disease. So it was because the virus ruined the immune system that pneumocystis corinii could infect the lung or that a certain type of malignancy could develop because the t-cells were not there to protect the person from the development of a cancer. So it was going to be a long way to make all of those connections. So its many years later and we still don’t have a vaccine. Now obviously the vaccine would be the best of all possible worlds for people with high risk or anyone, I mean we all get flu vaccines. The vaccine would be the best way to handle this because people could get the vaccine and then people would have a less significant risk of getting HIV. Just knowing it was a virus put us at ease that we did know it wasn’t some other thing that wasn’t easy to treat, but we still had to deal with the opportunistic infections. I shouldn’t say its just opportunistic infections, instead opportunistic events because the malignancies are not infections, so the immune deficiency resulted in a high level of certain malignancies as well as infections and they were going to continue to go on until we were able to figure out the best way to manage the immune deficiency.
When did people stop wearing the garb?
There was a time after a lot of study about the HIV virus that people realized how it was transmitted. You’re not going to get it transmitted by simple contact, visiting with people in the hospital room. There had to be a close relationship – sexual relationship or blood transfusion of blood that had been contaminated with HIV. So we knew after a while that those were the things that we had to take care of, and once we were more satisfied with the fact that the virus was not transmitted by casual contact – you know walking into the room, talking to people, shaking the hands with them – that there began to be a reduction in the safety garb that we had to wear when we didn’t know what the mode of transmission was.

When did application numbers turn around?
I think the main reason that turned around was that we had a new chairman of medicine that we knew kind of turned around the concept of having all these HIV patients by publicizing the fact that we had a very special disease here. He twisted the situation to make it more favorable to have people who were interested in infectious disease, that patient population, or the concept of finding with a brand new disease and working with those patients. So the number of applicants for the residency program was restored, came back up, and returned to its usual high level. It was in the late 1980s – Now that you mention it, I do remember he got there in 1989.

How did Rock Hudson impact the epidemic?
There were ton of people who were extremely famous who got HIV before that, especially for those of us who lived in southern Manhattan. A lot of them lived in Greenwich Village – the arts people, a lot of people in theatre. I think rock Hudson was more of a surprise for everybody because of the fact of getting HIV suggested that he might have been gay, which I don’t think was appreciated before. Other than that, there were lots of people getting infected and dying. I think that the medical community was aware of what was going on and what populations were involved. I know that GMHC and others were very fundamental in increasing funding for HIV research. I’m not aware, but I doubt that Rock Hudson getting HIV would increase funding or research for the disease or that it would give any more information to physicians about treatment. On the other hand, it may have affected the non-medical community. The people who were not doctors, not in health care, not nurses and so on.. This being a surprise to them may have triggered the concept that anyone is potentially at risk. So it may have had an impact that way, but I doubt it had a serious impact on the medical community itself.

Do you remember the numbers of heterosexual AIDS victims began to rise and how that changed things?
There were a number of times where there were changes in the community that were high risk. The next community was the heterosexual community, so it became apparent that it wasn’t just male-to-male contact that resulted in transmission. It could be male to female and the other big issue is IV drug users who shared needles. If one of the people sharing was positive with HIV, just some of the viruses contaminating the needle and then injecting that into another individual would transmit the HIV virus. So first it was the heterosexuals, next was the drug users, which was the largest group for some time. Now there is a resurgence of mostly young people – gay men – who realize now that having HIV is not a death sentence. Now they know that people on HAART therapy live a whole live so now they tend not to take precautions as seriously as they
should and now they end up getting the disease. While the disease is treatable, it’s better not to have the disease in the first place. One of the reasons for that is that an active person may continually transmit the virus to many different people and it’s hard to track.

**What was the impact of AZT on your response?**
There were a lot of trials on a number of these drugs as they came on the market. The biggest challenge with these drugs was that after a while, resistance to many of these drugs became apparent. Using a combination of these drugs was soon found out to be the best way to handle these because of the recurrence of resistance. There were issues now with some single drug therapies that present a problem, especially with patients that we expect not to be compliant with the medication – so people who take the medication for a while and then stop it and then decide they want to start it again after they have taken it and stopped it can become resistant. They can start up the medication again and it won’t work. So all of those drugs provided some improvement, were subject to some resistance, but the improvement was not complete and none of the medication extended the lifetime for a significant amount until the combinations began to be tested together.

**Can you describe the impact on the hospital?**
Whenever you have something that looks successful, everybody is happy with it. That happiness stops when you realize that its not doing everything you want it to do, and each time a drug is released that is better, everyone is happy that the research is paying off and you're getting better at treating the condition. But there were a lot of findings that also improved the outcome of the disease without affecting the retrovirus itself. For example, better treatment for pneumocystis a change in the delivery the type of illness that patients were presented to the ICU with. So that we saw a difference in what the patients had. We also saw that people weren’t dying anymore of pneumocystis when we had a little control of the immune system but better control of pneumocystis, especially when we knew there were other medications that could be added to the treatment such as steroids, which could make the patient better. So toward the end of the 1980s that the presenting manifestation of HIV was no longer pneumocystis. We began to see cardiac abnormalities – cardiac failure and other conditions that needed to be treated with truly experimental therapy and all of these had there periods of hope and success. But none of them did a complete job until HAART therapy was developed, and even HAART, the components of it change on a regular basis now.

**Was AZT effective at that time?**
It changed things because it gave people hope. It did have some improvement in longevity and it was beneficial. IDK how else to say it. It didn’t do everything that we wanted it to do, and over time it was replaced. In that time it was very significant drug because it did do a lot of good for people with HIV.

**Can you comment on the price of AZT?**
I don’t think we really had any involvement with the cost. We knew it was expensive. I don’t recall how it was being paid for by people who had no money. The likelihood was that the hospital probably picked up the cost. Its also very likely that the GMHC helped to subsidize the cost of the drugs. Its also possible that the effects of the GMHC’s lobbying on the government, may have resulted in some subsidy for those medications. Although we like to in general we like
to use the rational combination of therapies when treating patients with other diseases, when you come down to a condition when you only have one choice, then you have to give it. From the perspective of the physicians, its something that we know but it doesn’t alter the therapy. There’s no other choice, you have to give it.

**How did you react to protests at CDC, NIH, white house?**

Well we knew the protests were going on, but I don’t know if they did anything special for us. Also, I’m sure that there were plenty of doctors who were protesting too. But I don’t know how it really affected us in terms of the care that we were providing. Those were the political issues. Eventually the funding for research and management went up, and the increment for treatment for certain people with government insurance in new york state remains subsidized. Even today, decades later, there still is a benefit in the amount paid for the care of an HIV patient. It was at a more national level. It wouldn’t affect us except that it would be nice to get the drugs faster and the research faster. Other than that we had to face what we had to deal with and also we had a lot of studies comparing funding for HIV wit funding for other conditions so that conditions like cancer – there were so many people with cancer back then that doing these studies – there were such few people with HIV that the amount of funding that was being funded for HIV patients in terms of research was much higher per capita than for cancer. Of course that’s a ridiculous calculation because if only 2 people had it you still had to do the research and research is expensive. So doing it by that method doesn’t really do it justice. I think that as we had presidents that tended to be less conservative, there was greater interest in increasing funding. As we move into the latest changes in health care, as we attempt to get everybody treated for whatever their real needs are, things have shifted from the 1980s. So you just travel with the flow and work your job according to what’s out there. And there’s plenty of activists within medical care, so I’m sure we were represented in those activities.

**What were your thoughts on the CDC, NIH, and white house’s responses?**

I always tend to believe that when something is done, there is a real reason for it. I don’t necessarily like what is done, but the people making these decisions know much more about what their options are than I do. As you pointed out, Reagan cut costs for a lot of things except for the military and so it was obviously something that he had do because I’m sure he had a lot of supporters that he wanted everything done. Some that wanted more highways, schools, this and that. So that happens throughout politics, so again although I may not like the outcome, I don’t know what their options are or their budgets are or if I have the expertise to analyze it if I did.

Look what happened now – I’m extremely in favor of health care for all. I think Obama is doing a wonderful job in trying to get that distributed to all people. On the other hand I don’t know what that will mean for hospitals because there are safety net hospitals who need funding and if there are cuts in funding associated with the ACA, hospitals may close. You don’t like that to happen when you want to give more people the ability to access healthcare. So there are positives and negatives, you have to deal with it and see how it goes. It was the same thing back then just different framework.

**Do you think they were knowledgeable of what was going on?**
I think so. It’s hard to believe that with the CDC, the NIH just a few miles away that they didn’t utilize the information provided by those services to make those decisions. Those are government components. I know that the CDC publishes a periodical that counts the increase of certain diseases and HIV was monitored from the beginning. That’s government area and they have that information. I can see a president cutting the funding for something without even knowing how many people had it and how high it is escalating.

**Can you comment on the critique that doctors didn’t adequately relay the urgency of the epidemic?**

There are people like that making claims about everything. However, it is a federal mandate that all patients who presented with HIV had to be reported to the federal government. I’m not sure what the turn around timing was for that reporting, but it’s probably within 24 hours of a patient being admitted. I’m not sure what the time frame was for that, but they had to be reported. The federal government had all of that information from every doctor within the United States. I can’t imagine why a doctor would want to hide it because they would risk losing their license by not obeying a federal mandate, and what benefit would they have in withholding the information? I think the mandate was in place right at the beginning in 1981. I used to keep track of how many HIV patients we had at St. Vincent’s and we knew what the national figure was. We could watch as the rest of the country was getting more. In the beginning 1 of 6 AIDS patients was at St. Vincent’s and that lasted for a couple of years but then as our percentage fell, there was evidence that there was greater incidence of the disease in other parts of the country. That was there. If for some reason there’s a group of people that are suggesting this information was not provided, it’s on them to prove it. There are a lot of people who connect an issue with the people who are trying to correct the issue. I remember having a discussion with some friend of mine – this had nothing to do with HIV – who were pointing out that so many people who want to go to a doctor or a clinic to get their healthcare and are unable to get there because they have some kind of disability and the doctors need to do something about it. The obvious thing is that it’s not that doctors but the social workers. I turned it around and said ‘I agree with you. These people should have better methods to access healthcare and I have the number of the volunteer department so you can drive them there or help them walk there.’ Just because they’re seeing a doctor doesn’t mean that doctors have to fix it. Just because a disease is taking the lives of millions of people – hundreds and then thousands of people back then – doesn’t mean that the people trying to take care of them should stop treating them to do more things outside of their basic realm to get the disease to stop. There were plenty of doctors supporting the GMHC and other organizations who were part of it just like anyone else was. I wouldn’t take this valid unless they can show that doctors didn’t present information to the CDC or had lower involvement with patients with HIV as the general population. I think it ridiculous.

Personally the funding that they would have been given would have been for research and the NIH is where that’s done. While I don’t track the amount of money that the NIH gets and how much they request, although every year when there’s a budget there’s usually some kind of comment from the NIH that they need more. Those people were requesting more money. I don’t know the details of it but I know that the NIH was looking for more money for HIV research. They’re all doctors, not necessarily MDs, but MDs and PhDs. But a large proportion of them are doctors and I would say doctors in general made up a much larger component of people asking for HIV research other than groups that advocate for gay men like GMHC. I would estimate that
It’s very difficult for me to comment of homophobia. Being in the middle of Greenwich Village at that time, and now that I’m not there anymore, being in New York City, I can’t even think of a physician who I would know that might be homophobic. It might be true in the Midwest; I don’t believe its true at all in New York City. I don’t think it ever was in Greenwich Village. I don’t think it ever was in San Francisco or certain parts of Sydney, Australia – all big metropolitan areas have people who are gay and open. These people are friends of people who are not gay. It a continuity of people. I just can’t imagine a system that’s homophobic – I mean you can always find an occasional person but I don’t think that adequately reflects what life or medical care is in NYC, and especially back then in Greenwich Village.

**How did working with AIDS patients affect career?**
My career has been in intensive care. The greatest impact it had on me was during its first years. After the mid 1990s we were keeping patients out of the ICU by identifying patients with certain conditions more rapidly. I know that by 1986, 5 years after the epidemic started, that about 75% of our ICU beds were taken up by HIV.

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**Dr. Sharon Kiely – Interviewed November 6, 2013 and January 4, 2014**

**Describe your background before 1980**
I was originally from Belford, NJ and then moved to Redbank NJ when I was twelve. Both were in Monmouth County, NJ. I was in a catholic grade school and high school. I graduated high school in 1975. St Mary’s grade school and Mater Dei High School. New Monmouth, NJ was a

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doctors in general made up more of the support group than any other subgroup other than gay men advocacy groups.

**How would you respond to critiques of homophobia, racism and misogyny in medicine?**
Clinical trials were done like they always have been run. It is definitely true that research on anything tends to be focused on white people. It used to be, though I’m pretty sure this is not as true anymore, that it also focused on men, and that is a problem. Over time that has been improved upon to some extent, I think its fully corrected for women but it still needs more involvement of people of other ethnicities.
The theory back then, were talking about many years ago, was that what we were proving was must be the same for everybody. That obviously is not true. When you look at other diseases, such as hypertension for example, the cause and treatment of hypertension in blacks is very different from what it is in whites. Its only now that there are increased research focus on having adequate representation of all ethnicities in order to ensure that we have a better idea of what’s causing it. For some of those diseases the research should be specifically on a specific ethnic group. For example with hypertension, the studies should focus on blacks because it is a different disease than it is in whites. So you should do it in both groups, but you have to focus on getting enough volume of African Americans that you can say the research is valid. I would agree with their comments. I think its obvious that over time with HIV this switched. There has been research of people of various socioeconomic groups and various ethnicities. So for HIV its much better than it was before.

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suburban area. Then, I went to nursing school in 1975 at Georgetown. I was in the nursing school for 2 years and then I went into Georgetown College and graduated 2.5 years later. I switched, so I had 4.5 years in college. I ended up graduating Georgetown at 1980. From there I went to medical school from 80-84. At the end of medical school I interviewed in NYC for programs because I knew that my partner had his fellowship there. Then I started at St. Vincent’s in July 1984. We lived in the Village/Chelsea on W 15 St. Then we moved to W 12th St in 1986. I was there until July of 1988, when my family moved to Pittsburgh.

**Any aspects of upbringing that would impact approach to gays/ IV drug users?**
I was raised Catholic, and people didn’t talk about gay people. There wasn’t any overt hatred or that sort of thing. IV drug abuse was something that other people did. It wasn’t in our neighborhood or background. I had no context to understand that. I learned more about IV drug abuse in medical school. In my residency, certainly taking care of patients. When I got more exposed to patients, I became more familiar because lots of people with that habit show up in emergency rooms.

**Why did you choose to enter medicine?**
My parents got divorced when I was in college and I realized that I never wanted to be financially dependent on anyone. I was in nursing school and I saw my mother with six kids, no credit cards, no car, no money even though my mother only had a high school education, I did not want to be in that situation. I was already in nursing school because my father said that if I wanted to get any financial support from him that I had to go to school for a trade. I had the option of business or nursing school. I chose nursing applied to nursing school. When I got to college, I was first exposed to people who were just Biology or history majors. That was the first exposure to that because my father went to business school @ Seton Hall and my mother went to high school. My parents got married when my father was in college.

**Why did you choose to switch from nursing?**
One of my earliest jobs was as a nurses aid at Atlantic Highlands nursing home. I found the job interesting. I love talking to people. I felt that there was a greater purpose to it. It didn’t feel as empty or business or accounting. If a patient needs something, time dissolves. There is no concept of time. I always spent tons of time with my patients in my office - I loved it. I also did candy striping as a volunteer in my local hospital. I wasn’t afraid of blood and I found it fascinating. The first time I was taken to college by my Chemistry professor in high school we went to the anatomy lab at Trinity in Washington, DC – her alma mater. I saw they were dissecting monkeys and I was totally fascinated. I was like OMG people do this? It was awesome. Her name was Mrs. Zarilla and she said she wanted to go to medical school when she was a young girl. However, after graduating college she had to get a job to support her sisters going to college. She told me that she would love for me to go to medical school. I was like “WHAT?” I mean medical school didn’t occur to me when I was in high school. I was like “I can’t be a dr.”

When I was in Georgetown at nursing school I was really bored. I got good grades while doing little work. For me to get up in the morning and do something, I need to be challenged, so I switched. I did not tell my parents. When I finally told my father, he said, “Why did you do that?” At that point he was only paying me $800 a semester so I was confident I could put myself
through college. He said, “What are you going to do about a family?” He said “your children are going to be sucking their thumbs until they’re 50.” He was concerned that because I wasn’t going to be a stay at home mother that I would be a bad mom. My pediatrician even said to me, “you’re too pretty to be a doctor”

**To what extent did you know about gays and IV drug users before the epidemic?**
I really didn’t. When I was in college, my friend Marybeth from home, who went to a small college in NJ, called me to tell me that she was dating a girl. I said that’s cool. It didn’t matter to me.

Georgetown did not have a big gay scene. There were men who you presumed – including priests – were gay. But I didn’t avoid them. The first boy I fell in love with in grade school actually died of HIV when were in medical school. It was really early in the epidemic. I was sad. I knew he was gay and that he died of HIV. I was just sad because he was brilliant, young and handsome – the smartest boy in our class of 150.

**Describe work in NYC during the 80s.**
I was an intern in a transitional program in the medicine department of St. Vincent’s. That year I took a variety of things. I did medicine, psychiatry, and dermatology. A lot of people in transitional programs move on to radiology or surgery. At the end of that year it was understood I was doing that I would move on to the primary care residency program, which was in the department of community medicine at St. Vincent’s. I went directly into community medicine in 1985. That program was attractive to me because it had several key elements, which I found intriguing. They did home visits for elderly people. We had a homeless healthcare program, when I’d make home visits to homeless people in SRO hotels and shelters. They would come to clinic. I also liked that 6 moths of every year was in-patient on the hospital side and 6 months in the community. So half a year for three years, I engaged the Village community. We would be assigned to make home visits with a team of nurses. We would go to little Italy, soho, Chinatown – all these wonderful places. I had my own patients that I would see again and again, who remembered me - Just lovely people. I had my own homeless clinic and the same people would come back again and again.

**What was the first time you heard about AIDS?**
We had no idea what AIDS would be. There were a lot of unknowns. There was a lot of fear. In med school no one knew if it could be transmitted through a cough. Then people knew it was transmitted through blood or sexually. Any blood disease can be transmitted sexually – like hepatitis. Needles, sex and blood products. We heard of the hemophiliacs getting HIV, but we didn’t call it HIV then. We had tests that would see blood counts. We would see low white blood cell count and then the differentials, which would show the lymphocytes, were super low. That was the clue that it was abnormal. Then we had HTLV-III, which would see. Once the lymphocytes went to a certain level, patients would develop KS, pneumocystis and diarrhea – you know the opportunistic infections. We were dealing with a lot of those.

**How concerned were you about your own risk of contracting the disease?**
I didn’t worry about me. We just knew that if you were stuck with a needle – you may get it. Now, when you get stuck with a needle you put people on prophylaxis. Back then we didn’t have
that – you just didn’t have sex with your partner, not donate blood and basically sit and wait until maybe you got sick. It was very very scary. The only thing that could assure you was that the patient was ok. However, if the patient was gay or an IV drug user, you were unsure even if the patient was ok this week because the patient could get sick at a later point. I was in a Code once when the patient had AIDS and were were coding the patient. Someone carelessly left a needle on the bed and somebody got jabbed with the needle, which was horrible. We didn’t have safe needle procedures back then – there weren’t many hospital safety programs. We all were upset that someone put the needle there – it was dumb and unfortunate.

I had to do spinal taps and one patient that I had known for a long, long time in the clinic had toxoplasmas (toxins in the brain). He had poxmarks on the brain. I had to tap the brain to remove fluid from time to time. I also had to inject medication into it. When I got pregnant, he needed brain surgery and I went to see him. That’s when we had learned that he had disseminated toxoplasma. I was walking in the room, the patient was unconscious and his partner wasn’t there. He was an AIDS patient. I knew that his toxoplasmosis condition could harm the baby. In fact, if you contract toxoplasmosis early in the pregnancy they tell you to abort the baby. My baby stirred inside me and it made me stop before I walked into the room. I didn’t want to put my baby at risk. At other times, colleagues of mine offered to do certain procedures for me because I was pregnant. It was one thing to put yourself in risk as a doctor, but another when you’re carrying a baby. My environment was very supportive of me having a child. I had a chief resident who I got in a lot of trouble because he was a dweeb. One night we went into the room of a patient being admitted with AIDS and at that point we knew you didn’t need to dress up like a man going into outer space. This doctor had a mask, goggles, hair net – I mean he looked like a cartoon character. He said I needed to gown up to go into the room, and I asked “why?” even though he was my superior. He was just a jerk. That was unusual.

Medical professionals refusing to care for AIDS patients
I had heard of people that did, but I don’t remember seeing anybody – not at St. Vincent’s. The chief resident, Neil, who I mentioned was this way. I ran a homeless clinic, so it was not a big deal for me.

Do you know of Medical professionals getting infected?
I knew of doctors getting infected, but it was gay people getting it sexually. My best friend in medical school – her brother was a fellow at St. Vincent’s and he died.

Did recitation of Hippocratic Oath impact your approach?
I love that oath and I don’t recall that it did. I feel that the part of that that relates to compassion and the idea of literally putting your patient before yourself and serving applied to anyone.

What were your greatest day-to-day challenges?
Not knowing what was going to happen next. Well, you could have a person who was perfectly well one moment dying the next. It was not predictable. In medicine, you diagnose an illness, set about a course of treatment, see if it works. If it doesn’t, you try something else. It follows a pretty predictable path, more or less, or trial an error. You’re not always right. In this case you would have people who would be talking to you one minute and unconscious the next. The would develop rashes, fevers – it was very unpredictable.
**Did that change over the course of the decade?**
Yeah, because you were able to treat things. You were able to A, recognize them quickly and say ‘this is this.’ Although some of the early tests were primitive, you were able to say with all likelihood this is what’s going on. We didn’t do a lot with prophylaxis until we started to work with aerosolized pantamadine and Bactrim for pneumocystis pneumonia. And you felt like you were doing something. And more came.

**Did that change as different populations of patients began to be affected?**
The IV drug abusers – I don’t ever remember them not being in the mix honestly.

**Was it different with them**
The thing is you would know that if people had Kaposi’s sarcoma, they were gay. The IV drug abusers didn’t seem to get that.

**What were the hardest moments?**
It was exhausting because where I was working, the hospital was busting at the seams. They built a new tower. They were tearing down the old wards when I left. You would admit patients at night and it was nothing to admit 25 patients a night on call. Now, the residents are capped at 8 or 10. They can’t take anymore. At 10 they’re capped for the night I remember one night I had 30 admissions. I had 30 admissions on my side of the hospital and the hospital was split into two teams. You could be on the Colman building, which would be the new fancy building or on call for the wards. There were two teams on at night. I remember the night it hit 30, I couldn’t see all of those people. I was moving as fast as I could. My friend who was working on the other side came over and helped.

**Would you help each patient less?**
You would triage. There was no one else to call. In those days the residents didn’t do very much. The interns did everything and the attendings – you didn’t call an attending up at home unless the building was on fire. I mean, when you were a second year resident in medicine and in surgery, you were in charge of the entire emergency room. The whole emergency room – there was no attending there. So one year out of medical school and you’re running an emergency room taking care of all the heart attacks on Wall Street, taking care of all of the AIDS patients, taking care of all of the people with cancer coming into an emergency room. You were flying.

**What were the hardest moments in the outpatient clinics?**
Well we had several outpatient clinics. We had a homeless clinic and a primary care clinic. In our homeless clinic – We used to say when I was in medical school the hardest patient to care for was a homeless person with diabetes because in those times insulin had to be refrigerated and all of that. Then there became homeless patients with HIV and that was very hard because they would get sick frequently, they would fail to follow up and when there were medications, you had to take them regularly. It was just very hard.

**Did that impact how you approached treating the patient or what you prescribed?**
No we would prescribe whatever they needed. We had a lot of money and a lot of stuff that was available, so that wasn’t an issue. We would prescribe condoms, which was against the rules of the church.

**You had to prescribe them?**
Yeah because they were covered for people with public assistance. St. Vincent’s did not approve of us doing that, but we did.

**Would doctors get in trouble for doing that at St. Vincent’s?**
Yeah. Its interesting, when I got to St. Vincent’s they would check your immunizations, your titers of antibodies, and they gave me rubella. I needed a rubella booster because me rubella titer was low. When she gave me the shot, she said, “Well I know you’re newly married, but you cant have sex for three months now after this shot.” I was like, “what?” But I later realized that what she was saying was that you couldn’t get pregnant for three months. But in her mind there was no birth control and so you cant have sex. That’s what that was about – it wasn’t that you couldn’t get pregnant. If I were single, she wouldn’t have told me anything. They treated you as a patient with church doctrine.

**So the epidemic first affected gay men and IDU. How did the hospital handle that?**
His or her mission was to take care of anybody. I think the record is pretty clear on this. St. Vincent’s really in the hay day of the epidemic, all the beds were full and St. Vincent’s made a lot of money. But when new treatments came out and patients didn’t need to be hospitalized – that’s when St. Vincent’s went belly up. So I don’t think the hospital ever discriminated against anyone. It had a mission. The sisters of charity were wonderful.

When I was running the ER on a cold night like this, everyone would look the other way if I let homeless people sleep in the waiting room. People would say, “is he going in?” and I would say, “He’s fine where he is.” The security guard would just wink at me and not bother the person. It was a very lovely place to take care of patients.

**How is your perspective on AIDS as a doctor in NYC different from that of your colleagues in different parts of the nation?**
Well in my intern year, I went to Hawaii to visit my friends Joan and Jim who were doctors and they weren’t taking care of anyone with HIV practically. And they were keeping normal hours that did not compare to the ours that I worked because the need where I worked was so great. I said, the floors were full. The emergency room was bursting. The clinics were bursting. So it was really a hot bed. That’s when I learned that others had a cushy, in my opinion, internship experiences – it was pretty amazing to me.

**Did you feel like they were knowledgeable about it?**
To them it was just theory. It was something in a textbook or something that they had read about in a journal. They knew it was bad, but it was elsewhere. It was like if there was a random outbreak in Texas. It would be a far field from what you are experiencing.

**How did the AIDS epidemic affect your view of modern American medicine?**
In terms of American medicine, it was awesome to see how quickly the virus was isolated. There were very few instances in modern medicine, although it is still a very wily virus, where people
came together so quickly. In some ways I think it formulated a path for when SARS came out or other deadly things a way of exploring and figuring out what was happening. I think we learned a lot from HIV.

Well in terms of people in the NIH and worldwide collaborated and coordinated. Initially we didn’t know what was going on – don’t get me wrong – there were many years when we were flying without instruments, but I think that over time the medical research machine … It became very hot to understand HIV. It wasn’t a mysterious disease where like twenty people had it. You had thousands of people that had it like the other epidemics that happened. So it gave us a blueprint for universal precautions. The whole idea in health care, and I’m switching from research to healthcare, that you don’t just ask about the disease if you’re gay or use injection drugs, but you treat everyone as if they potentially have it. That all blood is potentially hazardous and those sorts of things. I just think we learned a lot.

So you feel like the response of research was fast and adequate?
I think we didn’t understand it initially and I think it may have been that – I mean it was initially isolated in certain pockets like San Francisco and New York that it didn’t really play to the heartland very much. I mean you didn’t just have farm boys dropping dead in the middle of the pasture. You had this world which, to the majority of Americans, was very foreign. It was very comfortable for us in New York, but for the majority of America and the majority of the world, the idea of the virus being limited to MSM in New York. We would say there were infected women, and they would say they’re just prostitutes or drug abusers. They were the fringe of society at the time. I think if it had been farm boys in the Midwest, I’m not sure if we would have jumped on it any sooner, but there wouldn’t have been the prejudice that existed at that time. But I don’t think the people taking care of the patients. You can say that you self choose the situations you are in. There weren’t a lot of people in my medical school class that wanted to train at St. Vincent’s in NYC.

Why did you want to train at St. Vincent’s?
Its simple: your father was there. I wanted to be where he was. I applied to many hospitals in NY, but my first choice was St.Vincent's and I got it.

Do you feel like the initial populations shape how research responded?
I only know what I read – that it did. People didn’t jump on it. There was some confusion. But now, I think from better understanding of SARS, even west Nile, any of these viruses, that we have a much more sophisticated response. More focused on the viruses than on the people. Clearly in that people were working on it – we were all working on it. In record time we had a test. We could test you for HTLV-III, we could test you for all sorts of things. So the medical piece of it went along a pace. The whole And the band played on theory – I mean if you were sitting in a bath house in Greenwich village and half of your friends were dead, you were feeling it a whole lot different than the people on the upper east side of Manhattan, just a 50 blocks away. A place like Greenwich Village and San Francisco, the community was very accepted. That was the community. There was no not accepting them. It wasn’t that.

Do you think the different neighborhoods of NY were supportive and knew what was going on?
Yes, but there was a lot of fear though because you just didn’t know how it was being spread. When my daughter was being born, there was this big rumor going around that if a mosquito was going around that had just bit a person with HIV and bit you, it could transmit. So people were closing their windows and looking for ultra thin screen and using bug sprays because there was this horrible rumor going around. Then there was me who was living there as a new mother, and I began to question if I was putting her at risk in any way.

**How did the epidemic manifest itself in daily life in the village?**
You just saw people and you knew they were sick. There were a lot of people walking around who were sick. They were bone thin, Kaposi’s all over their face. You couldn’t hide anything either. You were emaciated. You were terribly thin, spots on their face, just sick.

**How did the idea of quarantine manifest itself in hospitals?**
Patients with HIV were put in private rooms, or two people with HIV were put together, but we didn’t have an HIV floor. We didn’t have a section of the emergency room devoted to HIV – but we didn’t call it that then. We didn’t know what it was.

**I guess GRID or AIDS?**
We called it AIDS.

**How did the discovery of HIV affect the way you approached treatment?**
It was helpful because you knew it was in body fluids. We knew it wasn’t from breathing or touching. I thought it was exciting.
After the four years at St. Vincent’s we moved to Pittsburgh, where the AIDS quilt was rolled out at the Cathedral of Learning and people spat on it. It was filthy to them. I didn’t understand it. I was horrified. I thought we had moved to the end of the earth or something. I thought that I had landed on Mars.

**How about your coworkers in Pittsburgh?**
Well in Pittsburgh the only people handling people with HIV were infectious disease specialists. No one in general medicine took care of patients with HIV. The second they got HIV they were sent to an AIDS specialist. You were not expected to care for them and you didn’t, which was totally weird. In New York it was a primary care disease. If there was an infection, the infectious disease people would get involved. If they had a cancer the oncologist would get involved, because some of them got lymphoma, Kaposi’s, candida. So the oncologists or the infectious disease physicians would get involved when they had a problem, but you took care of them all of the rest of the time.

**But how did other doctors react?**
It was like landing in a foreign world. Most general internists had never taken care of anyone with HIV. They would get diagnosed when they got sick in the hospital and they would be put under the care of a specialist, and that is the way it still is today.
When we were at Allegheny General Hospital, we got a Ryan White grant. Ryan White was a little boy with hemophilia and all of the HIV funding now is named after him. You need to look into that. We had Ryan White funds at St. Vincent’s. When I got to Pittsburgh, I got to know all
of the people in the HIV community – Susan Hunt and Dr. John Mellors who was an AIDS researcher.

We applied for Ryan White funding while I was at Allegheny General and we got it. At one point, our HIV doctor was leaving, which would have caused us to lost our grant, so I got all of the general internists that I worked with to go to the University of Pittsburgh to get training in the advanced treatment of HIV. I went as well even though I was a senior physician at that point. I just followed people around and asked questions because the drugs and treatment options were different and I needed to be clear what I was doing. I became the supervising physician of the HIV clinic again, 15 years later.
It didn’t scare me. I think it scared a lot of people to take care of the HIV patients.

**Do you have any examples of that?**
Well I think it scared them not because of the people, but they would be treating a disease that they had no experience with. If someone gave me a patient with pancreatic cancer and said, “Sharon, you’re on your own,” I mean I would be scared. HIV in my lifetime has become a chronic disease, and to see people start to develop heart disease and things like that when they would be dead in 6 months when they were diagnosed 20 years ago is a pretty remarkable thing.

**When you think about the epidemic, what thoughts come to your mind?**
I remember one night when we arrived at a patient’s door and my resident who was supervising me was dressed like glad. It took him 45 minutes to gown up to get into a room. I was like “you are such a freaking loser.”

Other times when I would be doing invasive things on patients, you know where the risk of a needle stick injury or a splash injury were high – the likelihood that you would be exposed to bodily fluids was high – that the generosity of my friends who would step in to help. And then Gabriel, who I recently read a little bit about and I’m saddened to hear how he ended up, was very excited to do a research project. I was like “anything but HIV, Gabe. Ill do anything but HIV, or whatever we called it at the time.” He kind of looked totally disappointed at me, and he went “of course its about HIV,” and I was like ok. I was just so tired of it. I wanted to just do medicine. In medicine you’ve got nephrology, neurology, hematology, oncology, cardiology, pulmonary medicine, infectious diseases, endocrinology – you’ve got all of medicine – every bodily function in medicine, and all I did was HIV. Nobody lived long enough to get heart disease. Nobody lived long enough to have n stage lung disease. So I didn’t feel like my medical education what someone got at the university of Texas or something like that where you saw 4, 000 diabetics and then you saw another 200 with this, that or the other thing. I did HIV for four years solid.

**Was HIV mentioned in your medical education?**
No. You kind of knew there was this thing going around, but I don’t think I saw at Georgetown a patient that I knew was sick with HIV – in all likelihood I did though.

**How did Rock Hudson’s public HIV status affect the epidemic?**
I think that people were really just shocked he was gay. I think people didn’t realize he was gay. But people that were close to him said “of course he was.” To me, I just watched the movies.
I think to me, when Magic Johnson announced that he had it, it was a little bit more shocking.

**Do you think that changed the epidemic?**
No, well the statistics of the CDC show that more kids were unprotected after that announcement. It was very weird. I think as more famous people got it, people they could relate to, I mean some people never met a gay person or knew anything about a gay person. So I think Rock Hudson has been in everyone’s living room on their television. Magic Johnson had appeal to the masses as an athlete. But to me, it didn’t really mean very much.

**How did the approval of AZT affect the epidemic?**
Well I used it. We had Ryan White money and other things so we didn’t have any issues with people getting treatment. That was the good thing. I recall that a person without HIV couldn’t get medication for their heart disease, but you were able to get what you needed for people with AIDS.

**Do you think it was still accessible with its high price?**
I didn’t have any issues.

**What was your reaction to ACT UP?**
None really. I thought that they raised awareness. They were good in that way.

**How do you feel about buyers clubs?**
Never heard of that.

**How did you feel about the CDC, NIH and FDAs response?**
Before I was a white house fellow I didn’t really know what any of these organizations were. I was very much naïve. Before I went to my WHF interviews, I went to the squirrel hill library and I looked up all of the cabinet posts the president had and tried to understand what they did. I was entirely clueless.

I wouldn’t know what the CDCs role was. I used to get the MMWR, which was the morbidity & mortality weekly report, which would come in the mail. That was produced by the CDC, and I loved it. That would tell you what was new and that’s where I got the magic Johnson factoid that nothing happened with promiscuity or use of condoms after the Magic Johnson episode. In some perverse way, maybe kids thought that if he got it than maybe anybody can get it, so what the hell – keep the condom off.

Anyway, so I didn’t know what any of them were doing. I heard that the FDA held things up, but I knew that that had something to do with thyliminide. It wasn’t until I was a white house fellow and I landed in HHS that I became intimately involved in all of those agencies.

**How did your time with HHS affect your view?**
I was on the secretaries advisors group at the NIAID. That’s Tony Fauci, who was like the grandfather of aids, and I worked for Tony on his advisory group contributing the little that I
could, but they’re very much tuned into the suffering that goes on in the world and they focus on
the suffering.

If anything, the agencies, because of the lobbying and everything that goes on, what true
scientists struggle with is these big epidemics, these high profile, headline illnesses such as
Ebola, SARS, all that kind of thing. They get so much attention and there are innumerable
orphan diseases where people are dying and suffering immeasurably that they would love to have
the money to focus on cures for. If anything, they know that the global fund for HIV now is the
largest part of the budget. I think that they do what they can with relatively little money. (42:50)

What do you think of the Reagan administrations response?
I didn’t know what they did or didn’t do.
I was working with JDRF and their goal was to double the NIH’s budget. We had done a
blueprint in JDRF and that was in the mid to late 90’s and by the end of that decade we had
secured funding and were able to get that done.

How would you respond to critique that medical professionals didn’t relay the urgency of
the epidemic to the agencies?
There were reports. I think our ability to report has improved substantially. I think that people
now know that if you see something odd in medicine, you report it. There is more understanding
of what is reportable and what is not. Remember there wasn’t anything like this in anybody’s
experience because all of the big epidemics like polio, measles and all of this stuff were behind
us. Tuberculosis was gone. There were decades and decades of health

How would you respond to activist criticism that med community was racist, sexist,
and homophobic?
I didn’t experience that. We just did our research. I don’t recall that, but when you step back and
you look, as I was saying to you before. I think had they been farm boys in Wisconsin dropping
dead, I do believe we would have reacted faster.

How has working on AIDS patients in the 1980s affected your career as a medical
professional?
I think it has given me a lot more compassion. A lot more acceptance of ambiguity. It definitely
heightened my problem solving skills because you had to solve problems. If you had difficulty
with uncertainty, ambiguity and problem solving, you were in trouble. I came to realize that I’m
actually pretty good at those things, and I’m not frightened by them. I was just like, “oh this is
interesting. I haven’t seen this before. What is this?” and keep looking for answers.
That’s one of the things that my patients often fed back to me as a compliment in that I didn’t
lost patients when I was trying to figure out what was wrong with them. I kind of said, “we’re on
a journey, lets figure this out.” I wasn’t like, “I cant help you. Go find someone else.” I would
really stick with them.

How do you think the AIDS epidemic affected the medical community as a whole?
Again, I just think it made us aware that after those many years of a lot of discovery, that we still
are capable of further discovery. Even with the JDRF work, I was like, even if we don’t cure
diabetes, we might cure something else because its all in the immune, autoimmune, immunity system.
I think that it has opened up this whole world of molecular – and really genetic – medicine; the molecular or genetic basis of a disease. If you have this activity, you are 90% likely to get infected with HIV now. If you have this activity, like a splash at the bedside when you’re doing a lumbar puncture and something gets into your eye, you have a 0.001% chance of getting HIV. So we know these things now. We know the mechanisms of disease. We are really learning how things are transmitted, the host response, the response of the virus. Its fascinating. Its rapidly gotten too complex for me to understand anymore.

Can you talk about needle safety precautions and needle share programs?

I think that when we learned that HIV could be spread through needle stick, the move to universal precautions and industry changes in needle manufacturing were the embodiment of the realization that you could not determine who had HIV by looking at them.

Can you talk about HIV diagnosis and confidentiality?

Early in the epidemic, Confidentiality around the diagnosis was important because of the stigma to the individual and the fear about the potential for transmission to others. Over time confidentiality regarding the diagnosis now has special status in medical records and permission to share this information requires permission apart from general permissions similar to psychiatric and drug and alcohol abuse medical history.

Do you think that the physicians made some of these changes on their own, or was it the legality of it that made them so cautious?

I think doctors have learned to be cautious that medical record information is sacred between the doctor and the patient. We have learned that insurance companies and employers could use it against the patient. So I would say that. Doctors were doing things to protect patients privacy before the laws changed.

Dr. Craig Keyes – Interviewed February 5, 2014

Briefly describe your background through 1980

I grew up in Wisconsin in a small dairy farming town. I went to undergraduate school at University of Wisconsin and then Columbia University in New York. I transferred out and I transferred back to the University of Wisconsin when my dad got sick.
I came out to New York to be with my brother who lived here. We were very very close. I graduated from the University of Wisconsin in 1978. My emphasis, back then it was called a triple major, was molecular biology, forensic psychology and theatre. It was great.
When I graduated I couldn’t decide if I wanted to go into show business or go into medical school, so I came out to New York and I worked for a year and did some auditioning and decided that I hated to be evaluated by anybody. I just couldn’t bare the pressure of theatre, so I thought medical school would be for the best and I did that. In 1979 I went back to medicals school in
Wisconsin, but I did most of my rotations in the city of New York. I was coming back to New York. My brother lived with his partner at the time and we were all really close. I just wanted to spend time with them, so I was in New York probably half the time I was in medical school. I graduated from the university of Wisconsin in 1983.

Were you in New York for the rest of the 80’s.
Yup, I was in New York on and off from 1979-1983 and pretty much nonstop from 1981-2004 and then I went to Denver for three years and came back to New York.

Where were you living?
I was living down in the village with my brother and his partner, down in the west village.

And you did your rotations at Lennox Hill?
No I did my rotations at Mt. Sinai, NYU and at Columbia.

What comes to mind when you think about AIDS epidemic?
It was scary. It was palpable, but it was also quite understandable. It didn’t feel like paranoia in the least. Everyone in my brothers circle of friends, I mean everybody started getting sick. And it was just really difficult.

Maybe I can just tell you my trajectory and you can follow with questions. I’m pretty much tied with AIDS personally and professionally through that whole period.
In 1983 I was starting my residency at Columbia and I started my residency in neuroradiology. It was about the third week of August and my brother’s partner got sick. He got PCP and so I was just thinking, “God this is it.”

At this time a lot of the people at the gym were getting sick. I would go to the gym every day with my brother. At that time every gay guy worked out and it was a really tight, small community really. You kind of knew everybody. So people were starting to get sick and I was just starting my residency so I said I don’t think I can do neuroradiology because I think I had to switch out. I either had to leave or I had to study this new thing.
At that point it actually hadn’t yet been really well characterized. So I did what the Dean did, Gerald Thompson was a combination of internal medicine and geriatrics. I wanted to understand multiorgan system failure, so I got into geriatrics and that’s where it turned up. If you got into AIDS at that time.

So that’s what I did and so what happened was I finished out that first year and then transferred to Lennox Hill. Everybody with AIDS was there. When I say that I mean everybody at the time that were getting AIDS were gay and so you were either going to St. Vincent’s in the Village or Lennox Hill if you were living uptown or you were some sort of celebrity. I ended up going to Lennox Hill. I didn’t like St. Vincent’s. I went to Lennox Hill and I started my second year of residency there. By then my brothers partner got sicker and sicker and then by the time I was done with my residency which was in 86, he went back to England because he was English. I was just really worried about my brother and he came back and while. God I haven’t thought about a lot of this for a long time. Cause its really tough to relive all of this. I did this recently.
when I watched *The Normal Heart*. Oh my God. Larry Kramer wrote it as a play. I actually had a blind date with him. Haha.

**You had a blind date with Larry Kramer?**
Yes. Not joking – believe me I wish I was. He was so hostile. As I said it was a really tight knit community.

So I forgot to tell you I came from a really poor family. I went to medical school through the National Health Service corps on a scholarship. They paid for all of my medical school, but in exchange I had to work for them for 3 years it was. I worked in a medically underserved area. So the whole time I was in my residency, I was thinking what on earth am I going to do when I going to go to Montana to help with the Indian health service. I was like I have to stay here with my brother. So I wrote this grant for an HIV health system to be run through the NYC health and hospitals corporation and I went to Bellevue satellite clinic which then became the community health project, when them became Tell & Lorde, which is the largest charity clinic here in town. So that was my project and I characterized people in need of services for HIV in New York City as a medically underserved area, and it got approved. So I got to stay and build this program and run it.

**Do you want to talk about the challenges you faced with the clinic?**
So running that clinic was just great. Its what I had been wanting to be working on anyway. So I was trying to have the most patients possible so that drug companies would want to come to me to try out new drugs. I wanted to have access to the things that my brother might need. So then this clinic was a very large volume of people with HIV. It was very difficult because I knew a lot of them personally as well as professionally. It was a wonderful vibe though. A community health project within the gay community services center down on W13th St between 7th and 8th avenue. It was down in the west Village, very close to St. Vincent’s. At night it was an STD clinic, and it was during the day that we ran our HIV program. The city funded it through federal grants. The personnel responded to the national healthcare service corps because that’s how it began.

GMHC was starting up. Larry was getting really angry and he started ACT UP.

**Could you talk about your opinions of the GMHC and ACT UP?**
I liked both of them a lot initially and then I got disappointed in how political they became. By political, I mean that they both became kind of petty and there’s all this fighting within the GMHC about taking care of someone who wasn’t gay. Larry was just so angry at anybody who was working within any kind of infrastructure. He would come into the clinic and just start screaming at us because we were part of the federal health system and don’t you know Reagan is trying to kill everybody.

We would say, “We’re not trying to kill anybody, Larry. We were trying to help.” But he was just nuts. I had known him from before and so it wasn’t that difficult. But the whole time there was this parallel dynamic of worrying about my brother and going home, making sure he had what he needed, just trying everything new. Just doing crazy experimental....I cant even call them protocols. And my brother would say that he had heard it up the street and we would see if it worked. We were really tying all sorts of things.
So the experience though was painful, but so important. I remember seeing other friends from my residency and medical school and they were saying “God how can you stand it? Its got to be so hideous and depressing.” I remember thinking so clearly that I cant imaging looking back 30 years from now when somebody said, “What were you doing when AIDS started” and you have to answer, “Oh I was doing dermatology, cosmetic surgery or neuroradiology.” I said to them, “This is what’s really happening in medicine right now. I couldn’t imagine being anywhere else. So it was really hard, but there was this corps of docs. We would get these patients and every one of them would die. I had just a handful of patients that are still alive now.

So queer literature has been very critical of the medical system. From your experience, did you feel that homophobia was rampant?
I didn’t experience anybody getting turned away from a hospital. I certainly experienced kind of a ghettoization where people with HIV were managed in a separate time or in a separate clinic or if you needed to be referred for services such as a surgeon or a gastro neurologist, they would have open times Tuesday an Thursday mornings from 8-11:30 and that was it. First of all I had a sort of split life because I was managing this clinic and then I also had a private practice. So in the clinic our hospital services were largely at Bellevue or any of the city hospitals and they were used to anyone being sick. They assumed everybody was sick who came in and everybody got treated. I did not see that kind of discriminatory practice but I did hear that it might go on in other hospitals, but arguably not that much.

So how about the discourse around the disease, such as nomenclature?
I didn’t find GRID offensive. It was a descriptor. There was just so much confusion about it at first. It wasn’t entirely cleat that it was a viral infection initially. In fact everybody thought it was caused by poppers. Then they finally realized that it was blood borne and there was a big panic. Nobody wanted to go neat the ponds anymore because you would get AIDS because of the mosquitoes. In terms of the language that was used to describe it, I honestly experienced it as a neutral descriptor and then retrospectively inaccurate. I didn’t have an emotional response to it.

Did you personally feel any ill feelings interacting with other doctors?
What I experience of it was just that doctors thought it was crazy that I was putting myself in harms way. I didn’t feel like that. I didn’t ever feel I was ever in harms way. So a lot of them would be scared that they would be stuck by the needles and they weren’t afraid of being around me, didn’t want to be around it. But the one thing I will never forget has to do with medical education. I will never forget the chairman of medicine at Lennox Hill said to me after I finished my residency – they wanted me to come and run the AIDS unit at Lennox Hill Hospital. The Chairman of Medicine said ‘I think you’re going to really regret it at some point because AIDS is really popular right now and a gold mine for getting funding. And everybody else is getting cheated out of their funding. So it’s not going to be the focus forever. You’ve got to decide if you’re going to go with it and run that risk or expand and get a broader skill set.” I didn’t like that and reacted negatively to it. I was shocked that somebody in that position would even think that let alone express it.

So he was saying you shouldn’t get involved with AIDS because it was a passing fad?
Yes. He really thought it was a fad and that it just didn’t make sense.
What were your greatest day-to-day challenges?
The greatest challenges were not having great treatment. Being so limited in the help that I was able to provide. That was the biggest challenge. Every day you would run into that and wish you could do something about a complication or a particular complication but you couldn’t do it. The science was so work and so limited and primitive. It was very very difficult and just very hard to get your head around. It wasn’t all that different from treating cancer. Everybody who was practicing medicine was stuck saying take this and you’ll be fine, or we’ll cut you open and take this out and have it all wrapped up.
Nobody else needed have difficult discussions with people coming to establish a mutual understanding of what you are trying to accomplish and acknowledging how powerless you were.

What were the hardest moments?
For me the most difficult moments were talking to a patient who didn’t want to die. We had to talk about what we would do if we weren’t successful and that’s how we were going to work together and manage it all. It was just very painful because every time I would think about my brother.

Did the epidemic shape how you look at American medicine?
It did as a matter of fact. It totally changed how I think about medicine in this country and how I approach it all. I would never be doing what I would be doing right now if I hadn’t had that that experience. It was largely because my brother was part of it. He was the one who had the observation of the whole health system, from his understanding is wonderful as long as you don’t need anything. If you need a lot of stuff it’s a nightmare. I was complaining that I hated the system too. He said he thought it was my system. He said it’s the one you doctors set up. He told me to not sit on the sidelines and go into business school and do something about it. Nobody else seemed to be doing anything about it. So it really did change my perspective a lot.
HIV and how services got paid for and distributed to people that needed it really opened up my eyes to really how important it is for doctors to understand that its not just science and medicine that …?

How do you think western medicine changed?
I think many more doctors became more open to the idea that American medicine didn’t have the market cornered on providing aid and comfort. I think it really helped understand the prospects for a more holistic approach to medicine. By holistic I mean taking care of the whole person: the spiritual part, the emotional part, not just the physical.
The other thing that I think it brought - I think it forced the medical community to have to work with a higher proportion of patients who were really smart about their condition. It forced the medical community in particular to act more in a partnership than in a kind of a more dictatorial frame of mind. I think that was a good thing for medicine.

How did the discovery of HIV change things?
There was a lot less fear. Of course people were still nervous about a virus, but at least you weren’t thinking you would be breathing it. So hospitals became a little clear in their infection control procedures and there wasn’t nearly so much panic or nonsense on poorly staffed floors at
night with people who had limited education but were still manning the nursing station. So that helped a lot.

**Can you talk a bit about quarantining?**

Well what I experienced was that there was an AIDS floor at Lennox Hill. The argument publicly was that all the special needs could be served. Effectively all of the experts were on the same floor. All the support services and the infrastructure was all on one floor. Many of us knew at the same time that that sort of quarantining or isolation was also for the benefit of the public relations department that didn’t want to have to deal with all of these movie stars at Lennox Hill having to be on the same floor or the room next door to somebody with AIDS. Those people just didn’t want the ventilation risk – coming up through the heater or the walls or something. So residents had a tough time because they were caring for a variety of people. Trying to reconcile and balance the lack of information and the lack of sophistication among patients of the general populous.

**How did Rock Hudson & Magic Johnson’s statements change things?**

I lived in a different slice of the world so I don’t know. I thought it was certainly helpful when Elizabeth Taylor got on board. Everyone liked that a lot and appreciated the level of visibility, but I think in New York a lot of people already knew a lot of really famous people who had HIV. It didn’t have as much of an effect where I was.

**Did you notice changes in New York or the Village?**

OMG yeah. For an example, I was just talking to my brother’s first lover. I ran into him in a hotel down in Florida two weeks ago and we were saying that we think we were the only two still alive from that entire circle of friends. We had counted 28 dead and we were the only two that we thought made it. It just had a huge effect. Everyone was gone, and it felt like it was all of the talented people. It was all A-list crowds. You would just go to the beach and it was just wiped out of who was in the most prestigious houses. You would look at the people and you would say, “Jesus how did you get in here? Ten years ago you wouldn’t have even been allowed on the boat.” It was an enormous change.

**Did it change the neighborhood as a whole?**

Nobody wanted to be in the West Village anymore. I think that’s why Chelsea was born. It was just too painful, too unpleasant. All of the places for casual sex just all closed or moved up to Chelsea. Everything changed.

The other thing that was weird in terms of attitudes is that there really was this tremendous respect for the risk of HIV and practicing safe sex. About 10 years after that, by about 2000, it was clear that there were a bunch of people who hadn’t really experienced the fear of getting AIDS. Its really interesting to see people who were not as frightened as the people my age were.

**Want to talk about a bit more?**

We just thought that you couldn’t have sex anymore. You cant even jerk off with poppers. You cant do anything. You could use soap in the shower, but that was about it. And then after it was determined it was a virus it became more clear. And then when you could check and see whether or not somebody had it then at least you could engage in sex with them, but even so you would have to protect yourself. So it was very repressive.
How did the gay community organize with safe sex?
I didn’t experience it as the gay community coming up with same sex. There was a real big fight
about it. A lot of people wanted to have a lot of sex because they had fought for so long just to be
able to have sex. They felt like they had earned that and to now suggest that it was a bad idea to
have gay sex just seemed to them to be insane or just backtracking. So there was a lot of
difficulty with it, and GMHC did a really good job with that. They were very clear and very
descriptive. They just made it a lot easier. They created a lot of interesting and helpful classes on
safe sex, how to put on a condom, how to have fun with a condom. They would do that which
was extremely helpful for people with post test counseling. People who were negative were
wondering how on earth they could stay negative without killing themselves with misery.
I remember there was a lot of contention about that. Larry was insisting that everybody stop
having any sex. He thought everyone had to stop. I remember clearly him having one of those
tirades in the clinic waiting room. He would just go up to people and ask, “Are you still hav-
ing sex?” He would just be screaming at them. I think it was a pretty lively discussion.

What were your thoughts on the general populous’ knowledge of AIDS?
They had all read about it. They wondered what it was like in New York. For those up us who
did our residencies in New York or San Francisco, we got a lot of questions about what life was
like in those cities. It just seemed to be so densely concentrated in those two.
Its probably not so helpful because I had such a skewed experience. I was just in so deep that I
just had no idea what a normal doctor was experiencing.

How did the approval of AZT affect how you approached treatment?
It was thrilling, it was great even though there were a lot of unpleasant side effects. Just the hope
that there was something that could slow this down until there was a really effective treatment or
a cure . Really back then that’s what people were thinking about. If we could just hang on 6 to 8
months, maybe there would be a cure. Really it was just so great, and a remember clearly that I
got a lot of it in. We would get stocked by the health and hospitals corporation and then we the
manufacturers would stockpile all sorts of samples. I remember the guilt I had when I stockpiled
a bunch of it for my brother and two really close friends who I thought might not have access to
it. I remember so clearly that I had big sweat rings under my arm and the same day, Keith
Herring, the famous muralist with crazy cartoonist graphics that just were overt images of
penises as people, did this huge mural in the bathroom of the gay men’s health center building on
13th St. I remember so clearly that he was just finishing a mural in the mens room and I walked
in with a shit load of AZT stuffed down my pants. I had huge sweat rings and I thought, “Oh god
this is awful.” I remember he said, “Doc you’ve got to head home. You look horrible. Go get
some rest so you don’t get sick.” I felt horrible – he would think so little of me if he knew I was
stealing this for my brother and friends. Clearly, I didn’t care as much about what people thought
of me than I cared about getting my brother his medicine.

What did you think of the accessibility and price of AZT?
I was in a clinic that was able to dispense it and had a bunch, so I had access to it, but no it was
not unlimited. I had a limited amount to give and if you ran out you were just out of luck. People
who had insurance were ok, but its all the uninsured or under insured that had trouble. So we had
this big stash for the underinsured. The biggest stash in the city by far.
But oh no I remember very clearly it was tightly controlled and I had to approve any of the exceptions that people gave more than 2 weeks at a time. At the time you would think, why would you give them a month’s worth of medication if you’re not even sure they were going to live that long? That’s how crazy it was.

**Do you think doctors were prepared to treat these marginalized groups and their specific needs?**

That’s an interesting question. Of course I didn’t have any trouble treating gay people. I was also lucky because I had just done a rotation in medical school and internship training at Harlem Hospital. There I only treated IV users, not just for HIV but for all kinds of things. I was very comfortable and wasn’t really nervous about the notion of drug use or the complications associated with it.

We had a lot of IV drug users. In fact we had a huge number of guys that contracted HIV from contaminated needles who worked for the New York Department of Sanitation. Somehow because we were a city-funded clinic, they knew that they could come see us and not disclose their actual identity. We had probably 40 or 50 of them, and it was so clear that they did not fit in with the rest of the crowd because they were these big bruisers who ran the sanitation trucks all from Brooklyn and Queens. They were very different from the gay guys in the same clinic. I mean, then the clinic was even called the Gay Community Services Center.

Now that I think about it, people were much more uncomfortable with the IV users than they were with gay people.

**How so and how did they adapt?**

I think eventually, from what I observed, it just took more experience. It was just hard because I think a lot of people struggle with all of the … there’s just a lot of soft tissue issues coming through primary care when you’re dealing with IV users that you never encounter anywhere else. I mean there are all these abscesses and all this weird stuff and the smell of it - Just the whole thing. It’s just really hard to get your head around it until you get used to understanding just what it is. One you get used to treating it it was fine – that was my experience of it. I used to observe people who started off thinking, “Oh My God can’t we offer separate clinics for them?” And then they just shut up about it and got to work.

**What types of things would you learn from this exposure that would allow you to treat them better?**

Just understanding more about them. I just liked hearing more about their stories – what they’re dealing with and what their barriers to living better lives were. The most interesting one to me was just the whole challenge that many of the IV users had with disclosing to their sex partners that they had HIV or how they would protect their sex partners. It made sense because then if you were gay of course you had HIV; what’s to be embarrassed about? For IV users, they had to disclose that either they were having sex with men and they had to tell their wife that or they were using drugs, because those were the only possibilities then. It was very hard for them to keep their secrets. We had to learn to spend a lot more time on that than you usually would. There was much more of a mental health emphasis with the IV drug users than when you were with a gay guy.
What was your concern with personal risk? How did that transform over the course of the decade?
I wasn’t really that afraid of it until my first really bad needle stick. Then I was just ashen. I was a wreck. It was in 1989 and so I actually just started taking medication. This was well before people were even thinking about post exposure prophylaxis or anything like that. There was no such thought. To me, it was no different from taking a Z pack before going to a book store for a blow job or something crazy like that. You just would do anything you can to protect yourself even though it had no foundation in medicine. It was sort of insane. There was a level of fear at the time that prompted very dramatic action. I wasn’t aware of any fear that I had until that needle stick, but boy did that accelerate.
For about 6 months I was really scared and careful, but then I just got over it again.

Do you feel that matched that of your colleagues in NYC?
Yes I do. I mean every once and a while you would hear of a needle stick and shudders would run through you and you would be like super careful again. Triple glove instead of double glove. All those sorts of things.

Talk about medical precautions and how it changed?
Well the whole gowning up was ridiculous – all that stuff that’s over the top. We started pretty early getting rid of that, except of course when there was a lot…if people had really advanced TB and there was a real concern about exposure to TB you would do the mask and you would gown up if they had not just pulmonary TB but cutaneous TB as well and you thought you were going to get it on your jacket or something. We would continue to do that, but I think pretty early on in the hospital that I worked in they got rid of that. And then occasionally you would see some idiot surgeon come in dressed in a space suit. That ended in around 1985.

Your reactions to ACT UP?
I feel their concerns were valid. When I said they went on to become political, what I meant that there was an internal back biting. They are political organizations – I liked that, but I felt as though they became distracted by internal politics; who gets to direct the agenda, are we for gay people or anyone with HIV, those sorts of things. It became so distracting that they really diminished the focus and the efficacy of the organization. I was very impressed in how effective they were at getting attention by the media.
So you liked their tactics?
Oh yeah, absolutely.

What were your thoughts on buyers clubs?
What do you mean how do I feel about them?

You’re a doctor. Did use of black market drugs worry you?
Not in the least because I acknowledged early on that I was not going to be able to cure the and that I wasn’t certain about what the best approach would be. I saw my job as being one in which I would do whatever I could to assist learning about what the different options that were available to them. I encouraged them to explore of the options and make choices and recognize that they’re going to have to do what doctors do and make decisions on less information than they would ideally like to have. That’s how it works.
In fact, I found that one of the most fulfilling parts of my work was just a real partnership. Working out what additional information we need to decide whether or not we wanted to take this risk. It really opened up a new – I had never thought of practicing medicine like that but I found it incredibly satisfying.

What was your response to the CDC, NIH and FDA’s response to the epidemic?
It just felt very slow. You just felt like you were on your own.

Do you know why that was?
I didn’t have a conspiracy theory in mind. I just felt like they weren’t getting much funding, they weren’t coming up with the answers, and there were a million of other things that they had to do. Nobody knew what was going on or what to do.

Do you feel like more funding or attention would’ve made them do more?
Yes I do. I think one of the big failures was the lack of attention that was placed on public health and prevention measures. I think that the virus spread to a far greater extent than it would have would have if it had had better coverage and more rapid movement by the public health entities.

What were your thoughts on President Reagan and Bush’s responses?
Well I hated them both of course. I was really really angry. I think the best way to characterize it – Have you heard of the performance artist named Kiki and Herb?

No
For this particular project there’s one small piece you should hear. They made a CD of a performance at Carnegie Hall. One part, Kiki described – its this guy that’s in drag – he does this show and at one point he stops and says “The saddest day of my life was the day John Hinckley missed.” When he talks about that, the reaction from the crowd – because the performance artist had a huge gay following – got an enormous ovation. I think that captured for me how we all felt about Reagan. I hadn’t been able to characterize it in any other way, but that was basically it. It was about the saddest day of my life.

What do you think he could’ve done?
I think he could have said the word, for starters. He could’ve made it more of a priority to protect people who at that point were not infected. He could’ve made an executive order to alter the funding. Reagan was extremely skilled as a politician. He could’ve gotten more money, gotten congress to act in different ways than it did. He could’ve done a huge amount.

How do you think Jesse Helms’ actions impacted the epidemic?
I think that who suffered most were particularly IV drug users women and children.

Why women and children?
They had the lowest level of awareness of their potential risk and children didn’t have a prayer. Women who were pregnant and had HIV weren’t even aware of the risk for the baby. I think not having the funding to educate people and to screen and test sex partners at risk – particularly IV users who were men – I think that’s criminal. I felt that all along. So we could only explain him as under the control of Satan.
How would you respond to criticism that medical professionals didn’t effectively relay the urgency to the public health entities like the CDC?
Gosh I don’t know. I didn’t really feel like I was part of the medical community at the time. I didn’t connect with the medical community as much as I might have. I mean all of the reporting – all of my own personal experience with the doctors I knew and worked with did a lot of raising red flags and reporting – a real lot.

Why did you feel alienated from the medical community?
I didn’t mean to say I felt alienated, I just didn’t interact with the mainstream medical community as much. I identified with a network of physicians to whom I would refer my patients for specific issues, and that was pretty much my exposure to the medical community. I didn’t go to like AMA meetings and all that nonsense.

How would you respond to the accusations that the medical community was homophobic, racist, misogynistic?
I have to say I didn’t experience it that way.

How did treating AIDS patients in the 1980s impact your career?
My career was all about AIDS up until 1995. My brother died in 1993, and I knew that I would leave practicing medicine then. It just became to difficult to see people die because I would just relive my brothers death over and over and over and I just couldn’t do it.
At the same time, he had suggested that I think about doing something to make the system more responsive to people. So I did go to business school as he directed me to do. That experience colored my approach to the rest of my career. I haven’t been practicing medicine full time since 1995, and I don’t have an active medical license. I haven’t seen patients in years.

What is it you do now?
I develop clinical programs for large populations with chronic illness – HIV is one of them. I do this for large employers or insurers in the United States. Elsewhere, I do it for entire countries, like the ministry of health. In Mozambique I do a big HIV program. I do a heart failure program in Germany and stuff like that.

How do you think the AIDS epidemic effected individual doctors approach to treating patients?
Well I’d look back at the answers I gave earlier about our openness to non-Western medicine and our move to a work of partnership rather than dictation. I think it actually helped the medical profession or an expanded segment of the medical profession’s experience with IV drug use in the context of a whole life rather than a defining behavior of a patient. You didn’t think of people as an IV drug user – like “I have one of those coming in.” Invariably, you would start thinking of this guy as HIV and has a wife who is in a lot of risk and he’s too ashamed to tell her. You would just think about them as people, and I think that that helped out a lot. More people began to think in those terms.

That’s the end of the interview. Do you have anything else to say?
No – I’ve been talking too much.
Describe your work in NYC during the 80’s.

So basically I went to medical school in Boston and graduated in 1988. After graduating in 1988, I did a one year internal medicine internship in Boston at Cambridge Hospital. I will mention that it’s not NYC, but that was interesting in terms of AIDS exposure because that was internal medicine. What I remember is that in medical school, I can’t even remember when I graduated in 1988 if they ever mentioned AIDS at all in medical school. If they did, I don’t remember it. They had a whole section of courses on infectious disease and etc. If there were, it certainly wasn’t emphasized as a very important thing at that point.

When I did my internal medicine year, I did it at Cambridge. It was very interesting because it was also a place where there was lots of AIDS. It was a totally different population. What happened was some of the insurance companies – Harvard Community Health Plan in particular – they had decided earlier in the 80s that a good way to make a good profit was to identify people who were otherwise likely to be healthy, take care of themselves. They identified young single men who were gay in that area of Cambridge as being educated and health conscious. They essentially marketed to them because there was a large population there. Cambridge was also turned up when the AIDS epidemic started. It was also a center of AIDS even though it was a wealthy community. It was kind of interesting. So even in my year of internal medicine we had some exposure to AIDS patients early on.

In New York, I did my residency at Manhattan Ear and Throat Hospital, which is on the Upper East Side of New York. I did three years of ophthalmology there, so I was there from 89-92. I guess that that’s one of your years in the 80’s. At that time I was basically an ophthalmology resident, and I did what ophthalmology residents do. You take care of your patients with eye conditions, both their medical problems and their surgical problems. Quite honestly we were mostly self-absorbed and concentrating on what we had to learn, etc. It was not really a place having a lot of exposure to public health or public health awareness or even much awareness of what was going on in the world or the news period. People were just busy working hard in their own craft, etc. Anyway, it was hard to be there at that time and not have some exposure to AIDS patients. Most of the exposure that we had was that we also did in patient consults at Columbia Presbyterian medical center. We would each for a couple of months go up there every day and work with the other Columbia residents in Ophthalmology and we would divide up what in patients consults needed to be seen. In that time in the 1980’s if you had AIDS, it wasn’t like if you were HIV+ now. There was little specific treatment for the disease. There were treatments for the specific diseases you got: Kaposi’s Sarcoma, Pneumocystis corinii, pneumonia, or specific diseases that people got. Basically the patients who had AIDS were terribly sick and basically wasting away and a lot of them admitted. By the time we would have any contact with them, they were very sick and specifically when we would see them, they were sick and they had specific eye diseases – CMV retinitis in particular – that had a treatment. They treated them with intravenous incyclomere, but you knew when you were taking care of these patients that what you were really doing was temporary. For instance, their blindness might be postponed. Instead of immediately becoming blind, they might get another month or two or three. It was sort of swimming upstream and solving their vision. At the time there were a lot of studies and
everybody knew this, but the life expectancy of people who had AIDS and CMV retinitis was very short. In other words you knew that you were treating a disease, but that you were temporizing it in order to keep their vision better for a little period of time, but none of them lived past 3 months, 6 months. That was about it. They were all cachectic, completely wasted, and more than just sick: they were depressed. They had a disease that nobody knew they had. Then there’s the whole social overlay about how people got the diseases. Everybody around them was afraid of potentially catching HIV and AIDS too.

**Did they mention AIDS in medical school?**
I just don’t remember it, and I remember medical school well. Its not like it was a long time ago. I graduated in 1988. But I can’t remember them mentioning it. They probably mentioned it because it was already in the news, so how could you not. I don’t remember it though. I think its because the curriculum in medical school is not very responsive a lot to most current trends. They probably write the curriculum 3 years earlier, so I don’t remember them mentioning anything at that time.

**Did you feel there was a difference in attitudes towards AIDS when you moved from Boston to NYC and back?**
I would say it wasn’t a Boston or New York thing. It was first of all the understanding of the disease unfolded. People didn’t know what the disease was. Second of all, what happened with time they began to realize who was and wasn’t at risk. And third, as they started to find treatments for these problems, that changed.
In each of these places, I was surrounded by different socioeconomic statuses, etc. You mentioned when I was coming back from New York. When I finished my residency – that wasn’t that much after the eighties. I finished in 1992 – I briefly began to work for another ophthalmologist and I discovered that I didn’t like that, so I started my own practice. So I started in Southerville, Massachusetts which is basically a city, but its adjacent to Boston. To some extent, it’s a working class city. There were AIDS patients in that community, but it was a different group of people. It was mostly Haitian Creole, which was another risk factor. Nobody understood why Haitian Creole patients had it, but they were a high risk group, even when I came back in ’92. Even when I started my own medical practice I saw patients who had AIDS. You mentioned the perception of them. I remember very clearly there was another ophthalmologist across the hall from me in a practice independent of me and I remember seeing a patient who came to me in around ’92 and he said to me that he had already seen another ophthalmologist 3 days ago and he basically told me everything was fine and shuffled me out. I saw this patient and saw that he had florid CMV retinitis, but I realized when I asked to see the other doctors notes just to see what changed that he hadn’t even done the most basic things we do in the exam: dilate the patient and look at the retina. I suspect this was because he knew that the patient had AIDS and he was terrified of catching it himself and the easiest thing to do was to get him out of the office. I remember this patient very clearly, and remember this was a time when a patient if you waited more than a week or two, he weighed 60 pounds. If you’re talking about people’s… other medical providers, especially older medical providers who had not recently been in training, who had not recently been exposed to real hospital based care, sick people…. Most ophthalmologists are used to taking care of patients for problems, but they’re not sick in the same way, and those patients with AIDS were sick in a way that became partly your responsibility. It became very difficult for a lot of providers to deal with it. I think the younger –
at that time I was young. I wasn’t even 30 years old. Even forget AIDS, you had just been taking
care of a lot of sick patients, and sick in many different ways. So it was another disease – a
particularly bad disease – but not one that terrified me or others in my peer group to be taking
care of those patients.

Were there special things you would do to keep risk factors low when you were treating
AIDS patients?
Well we didn’t really do the public health treatment. I was an ophthalmologist and we treated
them for a specific disease. Much of that you left for the primary care doctor. To some extent,
people came to see you and it was hard not to think about why this person had AIDS.
At the time, we really just thought of people who were male homosexuals, people who were IV
drug abusers, and people for some reason it was Haitian Creole. For some reason these were the
only groups that we saw and thought about and knew had the disease. Of course that colored …
to some extent there was a personal responsibility of some behaviors that led to that that colored
it a little bit. Not a lot, but to some extent. We also didn’t have electronic medical records in
those days, so to access to all of their care in coordination with other doctors. At that time we
were much more acting in treating a specific disease and not their whole health picture.

Would you take added precautions?
There’s this concept of universal precautions, where you really just assume that everybody has
an infectious disease and you’re careful. At the same time that’s not really realistic ever and
people don’t really do that.

At the time, certainly early on, we weren’t certain how you could catch AIDS – If you touched a
person’s face who had tears on their face who had AIDS, then you might catch AIDS yourself.
So we took extra precautions, and part of the reason you took them was because you probably
should have been doing that anyways. Wearing gloves at all times, etc. I don’t remember being
paranoid about that.

Sometimes we would get a little more intimidated when we had to draw blood. So as an intern
we had to draw blood. As a resident you had to start IV’s with the nurse who does it all day long
and you, who do this once every two weeks, are in the middle of the night trying to start it.
Sometimes we would try to do these impossible things and do 10 sticks for an intravenous and
we would be extra cautious not to sick ourselves. But again not really in an excessively paranoid
way about that.

Could you talk about the Opportunistic Infections that you saw?
So the syphilis is not the same disease, but the risk factors that led to HIV/AIDS, commonly
people were also infected with syphilis. So there was also at that time a lot more patients who
had tertiary syphilis, and part of that is an inflammatory eye condition, uveitis. So suddenly there
was a lot of uveitis that was attributed to syphilis and we didn’t know what was going on. What
was going on was an infection of both of these things and you were immune compromised so
people were having a more florid case of syphilis. That’s a really different problem.
The others were actually opportunistic infections or neoplasures that only occurred in people
who had HIV infection. So CMV retinitis is an inflammatory condition of the retina. It has a
characteristic picture. It looks as if you took the retina and splashed ketchup on it and cotton
wool, and a mixture of that splashed on the retina. So it would progress very quickly and basically destroy the retina and lead to blindness. At that time, the only treatment was IV encyclomere, which was administered in an IV and required patient hospitalization for a certain period of time – like a week. They would get IV administration and eventually would return home, periodically coming back for more IV encyclomere. That didn’t help with the general HIV infection, but it helped with the eye infection in a sense of postponing the inevitable, which was vision loss. Later as antiretroviral medication became available, those medications also became more effective and there became implants into the eye later in the 1990’s. But at that time, those patients would constantly come back for nothing more than intravenous encyclomere. You would see them and you would see them unfolding over a period of time and then they would be wasting away and disappearing when they died.

**Do you still see patients with these issues?**
No. I see more patients now then ever that are HIV+. That’s partly because I now work for a public health commission that cares for a lot of indigent patients. It’s a sort of medical center home for a lot of patients who are HIV+. They end up with primary care doctors at Cambridge Health Alliance.

So we see a lot of them now, but most of them don’t have AIDS. Even if they have AIDS, they have – I don’t know if they call it in remission, but controlled. I would commonly say, “How long have you been HIV positive?” and they would say something like 15 years. Before they would only live a few months or whatever. They almost never anymore have these eye complications anymore. So we see them once a year and we tell them if their CD4 count comes below 100 they should see us and if below 50 every 6 months. In the 80’s they would all have problems.

CMV retinitis was the main one. Sometime they would have these unusual infiltrates under the retina. Nobody really knew at first, I remember clearly that we knew what existed, but we didn’t know what caused them. People even did things like retinal biopsies. You should know that retinal biopsies are essentially unheard of. Its not a tissue you usually biopsy, it usually causes complications to biopsy, but people were doing it to figure it out. Those turned out to be PCP, pneumocystis corinii of the lung can actually cause a corroidal infiltrate. SO there were occasional odd ball patients that we saw, odd meaning they would be in the hospital for a week and every day people look at them and didn’t know how to treat them. They didn’t know what they had, they would eventually call in the retina specialist who would say, “well we never do a retinal biopsy, but lets try to figure out what they have.” I remember that, that was a PCP corroidal infiltrates.

Kaposi Sarcoma – I don’t know if you know about that, but it was an unusual problem that nobody saw and then all of a sudden – and one of the main locations was on the eyelids, especially the mangiomias. They were red puffy looking tumor factions on the eyelids. Early on, nobody really knew what they were and they eventually realized it was a neoplasia only previously seen in elderly Italian men once every 100 years that were suddenly appearing all over the place. So those patients could be seen in specialty clinics and we would see how they would do some surgical incision of it. But it was understood at that point that we were dealing with an AIDS patient with this unusual disease that – I’m not sure if they had any intravenous
chemotherapy treatment – it probably did. We oversaw the surgical incision of the eyelids which was involved.

So you mentioned you worked on both the Upper East and Upper West Side. Were there differences between those two places?
The Upper East Side, Manhattan Ear and Throat, most of the people were wealthy and educated and they had sought out that place. Not completely because there was a clinic population too. So we didn’t see much HIV and AIDS there. I mentioned it before that my brother who was an ophthalmologist at the same time was training at NYU and NYU has Bellevue medical center. We used to have combined conferences and meeting and courses when I would see him all the time there and they had a huge number. We didn’t have hardly any at that time.
When I went up to Columbia – that was a huge medical facility center – and they had a huge population of people who were more indigent, which tended to be the people that had HIV/AIDS at that time.

Are you familiar with ACT UP?
Not much. I thought I first heard about ACT UP like 10 years ago, maybe more. I know some kind of political organization that thought HIV and AIDS wasn’t getting enough attention nationally, and they were some sort of protest organization, but I was much guessing that. I don’t know much about it.

Did you feel HIV/AIDS got enough attention in the early epidemic?
I didn’t perceive that it didn’t. In other words, it seemed like there was a lot of money for research being put into it. It seemed like the medical community was providing care the best that they could. It didn’t seem to me like it was a disease being ignored. I remember now that at the time they talked about the funding for breast cancer was whatever, $200 billion and they were only getting $3 million or whatever. So I remember hearing debates about that, but I did feel like there was a lot of effort being put in to find causes, treatments. But it was the nature of the disease that made it hard to find any kind of vaccine or treatment at the time.

Have you heard of buyers clubs?
I didn’t know about buyers clubs, but I did know about the FDA approval concerns. My wife is telling me there’s a movie about that now – Dallas Buyers Club. What I remember was that people who had this disease felt like the FDA was withholding potentially useful medications from them and when they had finally proven they were useful, it would be too late for the person to use it. Then people went to other countries. Of course that can be a dangerous game because the FDA is really not a barrier to developing good medicine. It can be said for the opposite – that is people using things that were not FDA approved – having complications. So I don’t know what I would personally do in that situation, but I do remember at the time that there were some people going to Canada or importing from Africa or all these other places. I don’t know exactly where they got the medications and I don’t know even as a provider whether or not what they were buying proved to be useful or more harmful. I don’t know the answer to that.

How do you feel about the FDA approval process, which changed because of the epidemic?
Its hard because this was a unique epidemic that just came out of nowhere and had a huge impact, and maybe the systems have to be more facile. But there is a lot to be said for having FDA approval for medications. There’s just problems if you don’t have FDA approval for medications.

We see the same thing in Massachusetts. They just passed laws that essentially allowed the decriminalization of marijuana and medical marijuana use. For instance, the organization that I’m a part of, were not allowed to prescribe marijuana because it may be that its not illegal to prescribe it in Massachusetts now, but there’s not FDA approval of it, there’s no certification of the quality of it, etc. The truth is that ingesting, inhaling or injecting something unless its known to be safe – not just legal – it cant be certified. That process in cumbersome, but the process is also what makes us somewhat confident in all of the things we prescribe as opposed to other things. There are an awful lot of people who think things will work, might word, did work – anecdotal information. I’m very skeptical of those claims. You really have to prove that something is useful or you could do more harm than good.

What are your thoughts on the CDC, NIH, FDA and Reagan administrations response? Again, I was a little self-absorbed at the time. It was not of personal concern. I remember the news stories, but didn’t feel like…. I knew some people were thinking it was too slow or not given enough attention, but I never believed that it was an intentional, deliberate or targeted avoidance. I think there were people, such as in the gay activist community, that felt like they were intentionally being ignored, or not treated or left to die. I never really believed that to be true. You could argue whether or not enough was done or quickly enough, but I was under the impression that there were only good people involved trying to do the best they can and maybe not enough resources… I don’t believe it to be true that people were deliberately neglectful.

Do you feel like there was bias to IV users or homosexuals in the hospital or on a national level?
I would say yes and no. I don’t think its as organized as people had claimed. I think that individual providers were far and wide a little bit concerned when they didn’t know what was really causing this, how you could transmit. They were worried about themselves, so there was a little bit of a bias. When they knew how people caught it they were generally ways that public frowned on things, especially intravenous drug use, etc. So that’s on the individual provider level.

At the governmental level, I dint give a lot of thought to it, but I would say that it probably wasn’t a bias against it. However, there wasn’t a bias in favor of it. A good example is the breast cancer business. This is a disease that catches everyone’s sympathy. You could never spend enough money on it. There wasn’t that kind of good feeling towards political policy towards AIDS. I didn’t perceive there was a huge bias against spending money on it.

How do you respond to activist criticism that the medical community didn’t adequately relay the urgency to each other and on to the government agencies?
I don’t know what to say about that. Again, I was a little self absorbed, doing my own stuff, and it all unfolded rather quickly. It really unfolded over a year or two. I really wasn’t deeply involved in it to know whether it was really true or not true. The thing is developing medical
treatments takes time. If you have a disease that kills in weeks and months once they know they have it, it isn’t going to be fast enough at a certain point. It’s like a house that burns down in 10 minutes. You can say that the fire department should get there in 3 minutes and put it out, but sometimes it isn’t possible. I don’t know if there was anything that could have been done to prevent the early deaths.

How do you respond to the criticism that the medical community was racist, homophobic and misogynistic in the clinical trials and hospital setting?
I remember people talking about that care of patients being racist and sexist and homophobic. At the time, I don’t remember what people were saying about the policies or the clinical trials were really that way. I don’t know. I never had that feeling, that concern or discussion. Its not that I’m blind to it – I believe that was happening on some level, but I’m just not sure how it was on a policy level.

But the clinical trials – to prove something takes time, to design something takes time, to get funding takes time. I just don’t know how that could have happened more quickly.

Do you think that things changed?
At that time you would take Haitian Creole patients. We knew there was a huge population of Haitian Creole patients that had AIDS and then the question was if they had AIDS because of a certain behavior like IV drug use, homosexual behavior, promiscuous sexual activity, or if they had it because they’re genetically predisposed? Did they have it for fortuitous reasons, meaning it was going to be rampant and it just needed some place to start? We really didn’t know that. Each of those groups had different qualities. You couldn’t lump them all together.

So IV drug users for instance, there were very few people running around the world arguing that IV drug use for recreational use was ok. So they’re already a population of people that to some extent the rest of the world frowned upon. It probably hasn’t changed that much. Today we see patients with all kinds of things and there’s some degree of – I mean you don’t blame the patient, but the patient did some behavior over a long period of time that they’re responsible for it. That’s different than patients we see all the time from Africa, where many many women come here and have AIDS, and they have it because they may only have a relation with their husband, but their husband has promiscuous sexual activity.

So the responsibility and the prejudice depends on exactly which group, but it still exists. It still exists, but it doesn’t change peoples behavior now. It exists in peoples thinking, peoples understandings, but I think people behave more reasonably than they did at that time.

How would they do it back then?
Well people were almost quarantined. If there was an AIDS patient in a waiting room, there was nobody else sitting in that waiting room. Now people understand that they’re not going to catch it from being in the same room as the patient or shaking hand. I think there’s a much more professional attitude towards approach to people period. These days it would be entirely inappropriate in almost any organization I work with for people to say anything disparaging about any subgroup of people. Its just not allowed, not ok, and there’s consequences. Twenty years ago, it was not that clear.
How was AIDS talked about amongst professionals?
Again, we were young professionals. I don’t think we talked a lot about it. We more talked about the individual patients. So if we saw someone who was an IV drug abuser who had lots of health issues, you would eventually see them and say, “well, we knew this was coming.” But there wasn’t much more than that. It was really just treated as a disease to be treated. I would even say that we were relatively distant from the patient or the patient as a person. We would just see the patient and they were so sick, there was hardly any communication with them anymore. We were just treating their disease, not really them as a person anymore because they were so sick when we saw them.

How has working on AIDS affected your career?
I wouldn’t say that it affected my career, but I would say I remember specific patients, experiences, interactions very clearly. If we were talking about 25 years ago and I can remember very specifically having to go into a room and having to take care of a patient who could barely communicate and was basically lying there in the bed weighing 65 pounds. Having to tell this person that I had to do an eye exam to figure out what’s going on and I remember to experience very clearly. They colored your whole life, they colored your whole professionalism, your whole approach to people and patients forever. It’s the specific examples and memories of specific events that were very unpleasant.

Could you give an example?
Well I just gave you one there. You would have the mission of going in to do that and that really is what I remember. Having to do that. You’d get called at 10 o’clock at night and you just had a pleasant meal with your family and suddenly you find yourself in the room with a talking, walking skeleton. I remember that experience more than once.

Dr. Keith Sanders – Interviewed December 27, 2013

Describe your work in NYC during the 1980’s
It was the early 1980s, so I was in the cusp of the realization…. First there was an epidemic of people getting these horrible opportunistic infections and nobody knew why. Then they discovered the virus – and there was the French team and the American team and they shared that prize and there was this test that you could do to find if you had the virus. If the virus was the cause of the infections and that was all in the very beginning of medical school and I graduated in 87,88. I spent an internship year doing internal medicine at Emory, and then from 88-91 I was at the neurological institute in New York doing training in neurology. By the time I had finished medical school you could identify who had HIV but there were very poor treatments.

I’ll just explain from the beginning – what you probably have heard, in the early years when the virus was identified and there wasn’t an effective treatment there was a vast fear amongst house officers- that’s a common term for interns and residents -That’s who I was communicating with and those were my colleagues in those years – that if you got a needle stick, maybe you were going to die. There was that fear that you had a risk of getting HIV and you could die from it. We didn’t know that the risks were low. Early on there were these antiretroviral regimens that
were really toxic and they would tell you to take them for a month if you got a needle stick infection to lower the risk of getting HIV. In the end like less than a handful of doctors ever got HIV. DON'T QUOTE ME ON THAT, but it was a really small number. That was the one big issue and the other was that we could identify what these patients were having, but we had poor treatment options early on. Those two things were prominent in my mind.

What were house officers?
In the old days, when you were a resident, you literally lived in the hospital. We weren’t living there in those years, but they still call them residents. The first year, your post graduate year one (PG year 1), was traditionally called the internship and then the next year was PG year 2 and 3. As a neurologist, I just had to do internal medicine for 1 year and then I had three years of neurology. If you wanted to be an internal medicine specialist you did all three years of internal medicine and then you would go into pulmonary or infectious disease or cardiology.

How did the epidemic shape how you planned your post graduate years?
Wow it didn’t really influence me. You may even ask if it affected how I delivered care and I cant recall an episode where that came up. We were always aware of it but I don’t think it adversely affected patient care. Internally we were worried about it but the numbers were small and the risk seemed small by any logical measure. There were some people who seemed overly concerned – who seemed more concerned than others, ill say that.

I just remember a resident telling me that he had had a needle stick from a patient who was HIV positive and he had not slept that night and he was just worried a lot. He ended up not getting HIV and he was ok. In those years were weren’t using gloves all of the time. For example, now when you would draw blood you would never not wear gloves no matter what you did, no matter who the patient. In those days you would draw blood and sometimes you would get a little blood on your hands. The gloves were restraining and constricting, making it harder to find veins. I remember reading of an early case that came out of San Francisco where a patient came out of the Emergency room hemorrhaging and they were trying to save the patients life and there was a lot of blood on the table and the patients clothes and even though some of the people were wearing gloves, blood got up under the gloves. The patient had an active HIV infection. An ER worker – it was a physician – had so much exposure to blood on the surface of his skin and I think it even splashed into his eyes. He did get HIV. It was a very rare occasion, but it was reported. It was worthy of a case report and that sort of thing led people to be scared. Personally though, I just remember that colleague who didn’t sleep for a night.

And then you would have testing in a month and the subsequent months. And back then the testing was so secretive. The results of HIV would never appear on the computer. You could check lab results on the computer. You had to call the lab and talk to the supervisor. It seemed to be so important and bad to have HIV back then that it was kept confidential and highly restricted so you couldn’t look it up on the computer.

How about now?
Oh yeah, now its readily available. Now HIV is like diabetes. It is a manageable disease. It’s a complicated disease, but now its completely different.
Could you describe more in depth what you were doing in NYC
The medical school for Columbia University is on 168th street. Its way up town. The medical center is called Presbyterian and the formal name was Columbia-Presbyterian. It was the first combined university with a private hospital forming a teaching center in the 1920s – they moved uptown. Rockefeller gave them a bunch of land up there. Its right by the entrance to the George Washington Bridge. I was a neurologist in training. We were diagnosing and treating neurological diseases and we had our share of HIV there in the neurology ward because the virus is neurotropic. It likes the nervous system and can invade the nervous system pretty readily.

Do you remember your first interaction with an AIDS patient?
I remember one distinctly because I had to see him daily for several weeks because he was quite ill with multiple infections. He was a ward patient. He didn’t have insurance, so he didn’t have a private doctor so the residents served as his main treating physician. He was very thin and had an abscess affecting his spinal cord that was causing paralysis.

He probably contracted HIV because he was an IV drug user. That was a common source of HIV because people shared needles to shoot up with whatever. So he had HIV and it was a bad infection compressing the spine and causing paralysis. I had to see him every day to check up on his neurologic exam. The main issue with me was the details of keeping his IV going because that was one thing the house officers were responsible for – making sure the IV was working so when the nurses gave him the antibiotics it would help. I don’t really remember much about him. He was pleasant.

There was never a discussion over why the patient got HIV. We were treating the complications of the infection.

Do you think Columbia’s uptown location shaped how you viewed the epidemic?
I’m sure that shaped the type of HIV patients that we came into contact with. The other hospital I had rotations in was Harlem hospital. Harlem Hospital is at 135th and Lennox, which is in a really rough part of Harlem. If we were on call you would spend the night there and you would not leave the hospital after dark. Even if you wanted to run across the street to get a coke and a snack - there was a 7/11 across Lennox Avenue – I’m not joking you would often tell the guard at the door that you were just running across the street to get the soda. I never had a problem, but I never left the sight of the hospital. I was wearing my scrubs and white coat, so they knew I was a doctor, and I was the only white person there. It was a very black, segregated, rough neighborhood and there was a lot of drug use related HIV complications in that neighborhood. In Harlem it was mostly IV drug user HIV patients, while Columbia was more of a mix because the neighborhood had a semi drug population but also had a prominent group of people from Columbia who had practices downtown who would hospitalize their patients up at Columbia medical center. We would get a mix.

Were there a lot of HIV patients at that time?
I would say that we saw more neurological complications of HIV back then. I don’t see that many now because of the highly active antiretrovirals. The nervous system would end up being devastated in the later stages of HIV and there was a whole new area that was relearned about the opportunistic infections and the brain. The numbers have definitely gone down. I don’t often get
involved at all. The infectious disease doctors currently manage these patients really well. The patients just don’t get that bad. We will see them, but its less.

**Please explain HIV and the nervous system**
The genetics of the HIV virus is the origin of its complexity. That’s why its been impossible to find an effective vaccine because the virus’ genetic makeup is so tricky and changes so frequently. The vaccine has been the elusive thing for 20 years now. The nervous system is susceptible to the virus itself. There’s two aspects of the disease: the virus itself and the way the virus devastates the immune system. It allows the opportunistic infection. So the virus itself will invade and can cause damage to the brain and the spinal chord. If left unchecked – and it probably proportional to the viral load – it can creep in beyond the brain barrier and affect the nervous tissue itself.

The virus can invade the blood-brain barrier and get in there. Its neurotropic. Drawn to it even.

**So it’s the virus, not the OI’s that attacks the nervous system?**
Well I am saying that there are two ways that the virus affects the nervous system: one directly and one indirectly by lowering the body’s immune system.

**Was the virus talked about in medical school?**
Well get this – before I started medical school, I worked in one of the hospitals in downtown Atlanta. I had a job there and my uncle was a surgeon there. He had told me of cases, and there was this group of young homosexual men who were getting these strange infections and this strange type of cancer and he was asked to biopsy them as a surgeon. He was kind of following them around discussing it with me and used an acronym called “GRID.” Gay Related Immune Deficiency, which was… I don’t know how long that lasted but obviously it wasn’t gay related. It took them several years to figure out what it was. In Atlanta there was a relatively large population of homosexual men in those years, so we saw a disproportionate amount. I was so young in training. That was before medical school and I was just an orderly or a technician so they didn’t let me interact with people.

It must have been touched on because the virus had just been discovered. The first two years of medical school are the basic science years in the classroom. We had a whole semester or two of microbiology when they explain viruses and bacteria and I don’t remember. I don’t think I learned about it in detail until the third or the fourth year of medical school out in the wards and it was very primitive what we knew that, that is compared to what we know now. Back then the way you tested for the virus was by testing for antibodies. You didn’t test for the virus. If someone had antibodies to the virus that means they were infected. However the antibodies were completely useless in fighting the infection, but that’s how you tested it. That’s all I knew about the virology of HIV. We were learning the different manifestations of HIV syndrome and the seroconversion time, the period when the person would be HIV- because the body would not have antibodies and two weeks later they would test HIV+. They had antibodies at that point, so that was the time of seroconversion.

I specifically remember a young man who came in and his initial symptoms were that he had a sore throat. Why would you get admitted to the hospital for a sore throat? But it wasn’t just a
sore throat. He had lab results really abnormal, serious immune system problems, and what is called a coaguable state. He was forming blood clots unnecessarily. So his coagulation system was affected and his immune system was affected, and the only normal symptom he had was a sore throat. Long story short, this was one of the seroconversion cases where he came in and his initial test results were negative for HIV and later on we figured out that he was positive and what we were seeing were the massive immune system effects of becoming seropositive.

**So you’re saying you didn’t talk about it in medical school**
Well it was the third and fourth year of medical school. Those were the clinical years. The first two years were in the classroom and felt like college. It’s a little intense, but the second two years were a bunch of rotations in all different areas.

**What year was that?**
Like ’81 or ’82. I was transporting patients to the operating room. One summer I was an operating room technician. I would clean the operating room when they were done. Yucky job. It was crazy what they would let us do back then. The next summer some of us got allowed to be assistants in the operating room. We would pass instruments and get trained to assist in the surgeries. It was completely unregulated.

**Do you remember how GRID was discussed in the hospital?**
Do you mean were people making prejudiced statements? I’m sure you’ve heard all of those opinions. I think there were people then and there are people now who thought that HIV was a punishment for something – I mean it never made sense to me. That’s not the way science and infectious disease works. Were not punishing anybody. Its genetics and epidemiology and that’s what won the day. I didn’t ascribe much to that. It didn’t ring true for me.

**Being in Atlanta, you were close to the CDC. How did this impact your perspective on the virus?**
Well when I was at Emory, in Grady, the teaching hospital downtown. They had really smart infectious disease doctors. The CDC was the national if not international center for smart infectious disease doctors. They wanted to come to Atlanta. So we had a bunch of smart HIV infectious disease specialists. I don’t remember any specific HIV interaction with them on that front.

**How about AIDS Activism and ACT UP?**
Yes I remember act up. That was in the 80s, wasn’t it? Yes Yes I remember that, but I remember that being in New York. I remember reading about it in the paper, about this radical stance. They were like, “were not going to take this anymore. Figure this out. Put this on the front burner” that kind of thing. They would compare the Hiv research money to other types, like heart disease, colon cancer and it was pale in comparison and they were very upset about that.

**How did you feel about ACT UP?**
I never had any direct interaction with ACT UP. Initially, I mean, these were angry men. It was a little scary to see them in the public domain acting up, but that’s what they needed to do to get their message across. Although my initial reaction was that this was a little scary because they were acting up, but I think I knew that they had a message and a mission and I think that was ok.
I remember thinking with ACT UP – it was like they were butting their heads against a medical enigma. Their hearts were in the right place. They were trying to get activism despite a horrible disease. I remember thinking, well they’re trying. There was research being done, but I guess they wanted more.

I remember a similar thing about 10 or 15 years ago. There was a group out of Boston and they got together trying to get people to research a different disease called Lou Gehrig’s disease, which is a neurological condition. They were frustrated because a slow pace of development of the research and I remember that changed the paradigm and raise money and started immediate clinical trials and break up the Lou Gehrig’s disease market. They ended up not doing anything more effective from what I can tell than the traditional pathway that research is done. That’s another very stubborn disease.

**How did you feel about organizations importing drugs not approved by the FDA?**
I have no knowledge of that.

**What were your thoughts on the CDC, FDA and NIH’s response to the epidemic?**
I guess I would have to say that the response was reasonable. I felt like they were taking ok steps. I was not struck that they were dragging their heels. Things could have always been done faster.

**What were your thoughts on Reagans response?**
I don’t specifically remember his involvement. I would have probably predicted that he wasn’t necessarily key on doing anything, was he?

**How would you respond to activist criticism that doctors didn’t relay the urgency of the epidemic on to the government?**
It doesn’t surprise me that it would appear such. Each physician and each hospital across the country would not have a common means of sharing data. What each little silo was experiencing was not effectively collated until years later. There should have been a better epidemiological means of tracking that. So I would say that that is a valid criticism. Its not like anyone was purposefully doing something wrong, its just that there could have been a more concerted effort earlier on. I don’t know how to determine that that was because of bias or just because people too busy with what their own actions are.

**How would you respond to activist criticism that the medical community at the time was racist, sexist, misogynistic and homophobic in hospitals and clinical trials?**
Wow. I don’t have any knowledge about the clinical trials. You mean the initial studies looking at HIV?

-Yes, people complained that they only researched white men.
Oh right, yeah That’s a problem. That kind of bias has occurred in the past in research, and I’m sure its occurring in the current. There were other populations. HIV was three parts, it was homosexuals, IV and then the small population of people with hemophilia – er people getting transfusions in general.
I had a friend at University of Virginia. He was in a fraternity in 1981. He had a pretty bad accident with a fraternity brother. He was in the back of a truck and had a big fracture of the femur. He had a lot of blood loss and he had to get a transfusion at the University of Virginia hospital. He had come to find out years later that he had HIV. For a while there was no ready test for the virus in the blood supply. He died of HIV complications, actually a brain infection. This was just years before they had the highly active antiretrovirals came around in the mid 90’s. That was another personal impact of HIV… It’s a strange virus – it affected so many groups of people and it was pretty devastating. (17:46)

How do you think the epidemic shaped your future career?
I don’t think it had a direct impact on my career. It is humbling to have close friends that were taken down by it. And even though they were IV drug users or homosexual men. Just like a car accident it was like a random act. I was never to blame a disease on someone’s lifestyle. It was an unfortunate consequence of that, but I don’t think that to blame ever entered my.

Do you think that was a prevalent thought?
I would say that most non medical people and people from the South with a religious background and those people with more traditional thinking were quick to say that this virus is a punishment. It was not chance. This is what they deserve. Well I don’t know what their next thought would be, or they suggest. That they not do research or we try to present this. I don’t know how far people would go with that argument. But I think the south has a lot of people that have a religious faith that is pretty old school were happy to find a way to make homosexuality even worse. They didn’t like it before, but they were like, “here’s another example of why that’s bad.”

Did you grow up in the south?
Yes. I was born and raised here, yeah.

In Atlanta?
Yeah

Do you think that impacted how you talked to people back home?
I didn’t really feel it in the direct circles that I interact with, either family and friends, but one step removed from people in knew the South, its not hard to find people that saw the virus was an appropriate punishment or transgressions they perceive. Its funny in the South – and maybe in the North too – there are vast differences.

Can you think of anything that made you experience the epidemic differently as a southerner.
I don’t know

You mentioned different patient populations between Columbia and Harlem Hospital. Was HIV looked at differently?
Yeah I cant remember specific cased that would illuminate that concept, but remember Harlem Hospital was in a pretty rough community. Almost all of the patients were charity patients – there were almost no one there that really had insurance. So we were caring for patients that were already below the poverty level or unemployed. It was a hard group of people. There was an
indigenous black population and immigrants there for whom English was not their first language. It was hard for me as a white boy from the South coming over with a Columbia residency for me to connect with those patients. That doesn’t really illuminate much about HIV. That was a background of Harlem. The community resources were nothing. They would leave the hospital, and whatever antibiotics you gave them, that’s about all they would ever get. Those times were tough.

**Did that impact what medications you would prescribe?**
I think that what little plans made for outpatient follow up. We had a neurology clinic, but it was over packed with patients. They were in there once a week. It was very disorganized. So it was pretty rough.

**How did that contrast Columbia?**
There was A, the patient population was more mixed. There would still be indigents, but there would be a good number of people with insurance. then there would be a social structure set up to coordinate outpatient care. There were social workers, clinics, people who would help the patients apply for Medicaid. So it was definitely a better patient experience. It was a private teaching hospital, Columbia-Presbyterian vs. Harlem hospital. I definitely remember that.

**You mentioned IV drug users were more prevalent in Harlem, how did that factor into treatment?**
IV drug users were prone to other opportunistic infections than the sexually acquired HIV patients.

**Can you explain this further?**
Well the injection drug users were very much prone to bacterial blood infections. There really was another epidemiology of infection in those patients than in the sexually acquired HIV patients. Again, there wasn’t a lot of openness about homosexuality or sexually acquired infections in those days. I remember there would be men and their partners at the hospital. They would keep their cards pretty close to their chests. There wasn’t a lot of sharing of information. They were there because their partner was there and they were concerned and trying to help. In contrast the injection drug users you would have maybe relatives there, but usually not. They were usually more loners. I remember that.

**So if they were alone, did that impact how they would act in the hospital?**
I cant remember if that had an impact. I think the sexually acquired HIV patients were more cultured. They were more well read and more knowledgeable about health matters than the injection drug abusers.
I mean with the injection drug users you had two diseases already. You had the viral infection and then you were dealing with addiction that was difficult to break. We were not able to treat the addiction.

I’m sure it happened once, but I remember one specific time when a patient was not in his room and was found dealing or buying drugs in the public area down the hall. We were so naïve, like “holy crap! He’s a drug user!” Well duh – that’s why he was in the hospital. We were surprised that he continued it in the hospital, but he was addicted. That’s what addicts do.
How do you think the AIDS epidemic effected the medical community as a whole?
Well on a practical level, it led to the emergence of infectious disease doctors. You know, I think that for a lot of them 10-20% of their practice is just managing HIV. There are so many new treatments and drugs and tests and ways of controlling it that you have to be highly specialized in that. But I don’t really look at HIV as different than other infections or environmental challenges that patients have suffered. Medicine has to struggle through and find the cause. There’s always rumors and theories about certain miasmas and evil humors. Medicine has a rough history of not really figuring things out and making bad assumptions for some time until science figures it out.

Dr. Peter Zeale – Interviewed January 11, 2014

Briefly describe your background up to 1990
I grew up in Bronx, New York. I was the youngest of 5 children. I went to Cardinal Spellman High School in the Bronx and then went to Manhattan College. I did two years as an electrical engineering major and didn’t like it, so I switched over to biochemistry. I finished my biochemistry degree in 1975 and then went to Georgetown medical school from 1975 to 1979. I started my internship in July of 1979 at St. Vincent’s hospital and finished training there in June of 1983. Those were the 4 years – 1 was an internship, 2 were residency and one was a chief resident program. I went into a private practice from 1983, a solo internal medicine private practice in the Greenwich Village, Chelsea area of Manhattan, which is where I remain today in 2014.

Was your high school catholic?
Yes it was. I had an all catholic education. Catholic grammar school, catholic high school, and Manhattan and Georgetown were both Catholic universities.

How do you think that played into your approach of AIDS patients?
I don’t know if it did at all. I do think having a Catholic background gives a certain amount of compassion that one has. So maybe that affected it a little bit, but I’m sure non-Christians would have had the same approach to treating aids patients. I’m not sure it affected it in any great degree.

Most of your life you lived in NYC. How did your background as a New Yorker shape how you saw the epidemic or how the epidemic changed NY?
Well growing up in the Bronx, it was a very Irish, Italian, Jewish neighborhood. Growing up I did not have much exposure to the gay community in all honesty. Obviously when I went to St. Vincent’s as an intern, that was probably my first exposure to the gay community in the ER and treating patients. I didn’t come from a background – I didn’t have any gay friends or gay relatives. On the flip side of that with drug addicts, I didn’t really have much experience being exposed to drug addicts, although I’m sure in the Bronx there were plenty of them. In my area it wasn’t a major issue. So growing up where I grew up, I had very little exposure to the two groups of patients that actually were mostly affected by this disease.

How did you feel when you started interacting with those two populations?
In all honesty, I never feel like I treated them differently. It was a learning experience understanding certain gay practices which I wasn’t exposed to. I was accepting of them as people – whatever they wanted to do was fine with me. I never had any disdain of their lifestyle. Over the years – not so much as an intern or resident, but as an attending having private patients – had plenty of gay patients. I totally accepted them as just other patients.

When they first came on, we were all concerned about how infectious this was and how much of a risk it was to treat these patients. I must say that’s looking back 30 years ago. I’m sure that went through my mind in the emergency room, concerned about getting needle sticks and things like that. I’m sure that there was a certain amount of fear that, “could I contract this by even touching them?”

A lot of what you are asking is 30 years ago, so I’m going to try to think back to what I felt. I must be honest with you. I can’t remember what I did yesterday as I’m old. It was 30 years ago, but I do remember having a certain amount of initial fear of how close you could get to them. Should you wear gloves all the time? I don’t think we did that and half the time, before we knew what we were dealing with, we didn’t know what their illness was. The vast majority of them came in with these febrile illnesses and pneumocystis pneumonia symptoms. We just had no idea what we were dealing with. But I think there was a fear initially as I try to look back at taking care of them once we knew what the whole epidemic was like.

**When you think about the epidemic, what comes to mind?**

I’ll tell you two stories. One may have been one of the first cases at St. Vincent’s that I saw either during my internship or first year as a resident (80-81) and I remember having this fellow come in with this fever of unknown origin. We really didn’t know what was going on and I remember he might have been the first case at St. Vincent’s. He eventually got admitted and had pneumocystis pneumonia. I met him in the clinic – you were assigned patients. Whoever comes in, the next patient you take. I remember this guy just having fevers, night sweats, weight loss and eventually ended up getting admitted to the hospital, but this was after several weeks of being seen in the clinics and running things by your senior resident, and attending in the clinic and really nobody knowing what this fellow had. He ended up having this pneumocystis pneumonia.

This was one case, but another case that sticks in my mind very well. It was a very difficult case – a young girl. I was attending, so it was probably around 1986 or 1987. She was the daughter of a patient of mine, and she was probably around 18 or 19. She came in with certain symptoms of again fever, sweats and I actually ended up having to do an HIV test and it ended up positive. That was probably the most difficult thing – having to have her come back with her mother and having to tell them in the office that she was HIV positive. She had unfortunately had slept with a bisexual man. This was her first sexual contact according to her and she eventually did die several years later. I can vividly remember sitting down with her and her mother and telling her this, and it was quite difficult. This was probably around 87 or 88 so people knew about the epidemic and knew how devastating it was. That was a difficult case as I remember.

**Could you explain more in depth your work during the 80s?**
I was an internal medicine intern and resident. You could either be in internal medicine, pediatrics, OBGYN or surgery, so internal medicine is taking care of adults non-surgically. You’re on call in a staggered every 3rd night system. You would follow certain patients in the hospital. Some were private patients of private attendings, but then at that time there were a fair number of what we would call “service patients,” who had no insurance and taken care of by interns and residents with the supervision of an attending physician.

At St. Vincent’s we were lucky in a sense that we had a large service population so you had a little more autonomy about making decisions and taking care of them. You would follow anywhere from 10 to 20 patients, which would be on your service. These were people in the hospital, obviously they were sick with various medical problems, whether it be heart attacks, pneumonias, abdominal problems, urinary track problems. The cast majority were on some sort of intravenous medication or some sort of infection. You would follow these people, admit them, take a history and physical, write orders, write an admission note, discuss it with your residents, discuss it with the attending the next day. Then you would follow these patients until they were discharged from the hospitals and then follow up with them often times in the clinic. You would meet in the clinic once a week. I believe it was a four hour session on an afternoon, where you were seeing either patients that were discharged from the hospital or patients that had chronic medical conditions for whom you would be their doctor for the 4 years you were there. You would follow them for their high blood pressure or their diabetes or heart condition. Its all non surgical – being an internist there’s no surgery involved. These were all adults , so we weren’t dealing with the pediatric population.

Did this change when you opened your private practice?  
I went into private practice in 1983 and opened up an office. So how does one get patients to see you? One of the ways was accepting patients from the emergency room. For example, patients would be admitted to the hospital and they had(n’t??) insurance and wanted to have a private doctor, but didn’t have a private doctor at St. Vincent’s. So you would accept them from the emergency room and build an emergency room. You would get referrals from nurses and other patients. Starting out a new practice is very difficult. You may only see one or two patients a day in your office and you had other types of jobs to help you support yourself as you build a medical practice.

How did your idea of personal risk transform as more medical knowledge came out about the virus. Did it match your coworkers?  
I think as time went on it was obvious that you couldn’t contract this by touching an aids patient with your bare skin. That fewer quickly went away. Were there interns or residents that didn’t want to deal with AIDS patients? I would say yes. I can’t remember a specific example of someone refusing to care for an AIDS patient. I don’t think anyone ever refused to admit an AIDS patient. I do think there was a sense in some people that there was still concern in drawing blood from them. That was an activity that you had to be careful and you didn’t want to have a needle stick with their blood into your system. That could certainly lead to problems, but I’m sure that a vast majority of people at St. Vincent’s were very caring and never looked down on these patients. Remember these patients were very sick often times and you often times said to them that you knew they were going to die because at that time there weren’t really great treatments like they have today. There was a certain amount of concern for these patients. Was
there the odd person that might not have had that, I’m sure, but nothing really sticks in my mind where someone absolutely refused to deal with an AIDS patient.
The drug addicts were a little bit different – ill be honest with you. The drug addicts are tougher people. They had an edge to them. Maybe there’s not as much compassion with their plight as there was with the gay population or any other heterosexual person that got this disease because some of them – not all of them – had this nasty attitude and they were always looking for drugs. I think a lot of interns and residents had a very different opinion from that group of people that came down with HIV.

**How was treating an addict different from treating a gay patient?**
Tolerance. Often times they would want more drugs. They would be more nasty to you. A lot of the time they would sign out of the hospital against medical advice and in all honesty you were happy to get them off of your service. They were often times more trouble than they needed to be. Looking back at those patients, I would say that we did treat them differently. I think we had less tolerance and we would love to get them off of our service. Often times they would just leave from the hospital, elope from the hospital. Half of them, they were still looking for drugs, and how do you continue their narcotic addiction while they were in the hospital. So they were difficult I would say.

**Would they have different manifestations of the virus? Different opportunistic infections?**
It’s a good question. I’m trying to think back. The major diseases I remember were the pneumonias – the pneumocystis pneumonia. Whether they had more parasites in their gut than the other populations – it’s hard for me to remember back. The patients that had the skin manifestation, the Kaposi Sarcoma, I think maybe there were more gay patients, I remember, but then again it was a long time ago.

It was interesting you would see these purplish legions and it was basically cancer. These were skin cancers that these patients were developing because of their immune deficiency. People had very unusual infectious diseases that would not usually cause harm on one with a normal immune system. There were some brain infections, some parasites in the brain, and then whole other cancers, some lymphomas that occurred in these patients – intestinal, gastric lymphomas that they would get because of their immune deficiencies. But I don’t know if the IV drug users really had much difference – I’m not really in a position to remember that right now.

**Do you know of any medical professionals that got infected when caring for AIDS patients?**
No. I remember people having needle sticks. I remember at some point down the line you would be treated prophylactically with some antiretrovirals, but I don’t remember any specific doctor that contracted that.

I do remember this hepatitis C – I can think of two cases, but that was around also. But HIV I cant remember a physician or nurse that I knew who came down with HIV.

**How would they react to needle sticks?**
You would go to the emergency room and probably get a tetanus shot. At that time it probably got some form of immune globulin. You would get hepatitis a immune globulin. I don’t think at that point there was anything else to do, to be honest with you.
As time went on there was this three drug cocktail that you would have for several months while you were being monitored. At the beginning it was just a tetanus shot. I’m sure, looking back, that I have had needle sticks and I can’t remember specifically from an HIV patient, but I think over the early years I had some needle sticks myself – no consequences though, thank God.

What were your greatest day to day challenges when treating AIDS patients?
It was really just trying to get a diagnosis initially. Often times the pneumonia patients would need to be bronco scoped to try to make a diagnosis.

Obviously, you wanted to make these people better and get them out of the hospital. Some lingered for a long period of time because they had daily fevers and then different types of infections, so some of them lingered on your service for a long period of time. There was at one point at St. Vincent’s an HIV floor was eventually set up and if you reached rotation on that floor you were usually with an infectious disease doctor. All of those patients – you had a pretty intense experience with them. Being a doctor, you like to see people get better. You like to give them something to make them better, and these patients didn’t get better. It was a little frustrating.

Very early you didn’t know what you were dealing with and you had to rely on your infectious disease consultant to guide you with the treatment and what you were going to do with these patients. As an intern and a first or second year resident, I had no idea what I was treating.

Was it harder returning back than usual?
It would be frustrating. It wouldn’t be all that satisfying in the sense of seeing the patients get better. You would see these patients several times a day. Obviously you’re in the hospital all day. You’re being called by the nurses for all these different fevers and doing blood cultures on them. Was there a sense that I wasn’t doing much for them and this is frustrating and not all that satisfying because the patients weren’t getting better? Yes, I’m sure that was part of it.

If you ask would I prefer to have taken care of non-AIDS patients? I would probably say yes. Not from the point of view of getting sick from them, but from the point of view that they were a lot of work. As an intern and as a resident, your day was a long day and you wanted to get through the day. I’m being a little selfish as I remember, but if you had a lot of AIDS patients on your service you were very busy taking care of them. It wasn’t, as I look back and try to remember, fun. You learned a lot, but I don’t know if it was gratifying or not because they were very sick, they were very debilitated, and you just didn’t see the success that you might see with seeing another patients who, after 3 or 4 days treating their pneumonia, they got better, and they leave the hospital. After 3 or 4 days, they’re happy, you’re happy, you did sometime. With the HIV patients, they were always sick and did take a lot of your time. As an intern back then, and times have changed, you would be there for a lot of hours. It took a lot of work to take care of several of them on your service.

What were the hardest moments?
As an attending, I must be honest with you, early in practice I was taking care of HIV patients and toward the end of the eighties it finally became clear that taking care of them was really a sub-specialty in itself. Some of my colleagues who were general internists did go into more HIV-
specific practices where you would know that this doctor did have a special expertise in taking care of HIV patients. You would refer your patients to them. As with any other specialty the people had the most experience dealing with them and they had a better outcome.

So by the end of the eighties, did I have HIV patients? Yes, I never shunned them, but it became clear that patients were actually seeking out internists who had a very strong HIV background and I was not one of them to be honest with you. My practice, though it was in Greenwich Village & Chelsea, did not evolve into an HIV practice. There were several internists on staff at St. Vincent’s who were HIV doctors. Some of them were gay, themselves. A fair number were, as I remember looking back, but not all of them. You would be very honest with patients and say if you diagnose somebody as HIV positive, you would treat them with some antiretroviral for a while, but after a while you would say “look, I’m an internist and not an HIV specialist. Il give you the name of this person who deals with this,” and it worked out for everybody. The patient would get better care because they were being cared for by someone who only took care of people with HIV.

Now days, I haven’t seen a new HIV patient in years. Early on when I went into practice in the mid-eighties I did take care of them, but I think in the late eighties where it became more clear that people did go into this as a sub-specialty, that they were doctors who had the interest of taking care of them.

Do you think gay doctors were better suited to treat patients with AIDS?
I don’t know if they were better suited, but remember St. Vincents is in Greenwich Village, which has a large gay population and there were a fair number of doctors that were openly gay. People knew that they were gay. Whether they went into caring for HIV patients because they knew more about the whole lifestyle, etcetera, I don’t know. There were a handful of straight doctors that became HIV specialists. Clearly, some of the bigger HIV doctors were gay as I remember.

It was hard because you had to refer other patients?
As an intern and a resident, it was hard because of the nature of being an intern or a resident is that you have a 14 hour day and if you have a lot of HIV patients on your team, your day is longer. It’s a busier day, and they’re more ill in the hospital. They took a lot more of your time and you’re trying to get through your day as an intern or resident. We were working 90 or 100 hours a week and I think it was difficult because they were so sick and the natural desire is, alright I have a certain number of people to take care of and these 4 or 5 AIDS patients are going to take most of my time up during the day. The other 15 patients I can see they’re not as sick. So I think the degree of illness– again I’m saying this as a house officer, an intern and a resident – took up a lot of your time, and it affects you. Nobody was getting out early those days. Everybody was getting out very late. Some of us got out later until the work was done.

Was there a moment that you were going to spread AIDS to other patients?
I don’t think I had that concern. I knew there were concerns if the patient was in the same room as an HIV patient. Somebody came in – somebody with pneumonia – and he did not have HIV. His roommate came in that night and he began asking, “you know that guys coughing. Am I going to get it?” And you knew the guy had HIV. At that time, they weren’t quarantining
anybody and there were a fair number of patients who were mixed in together. It was kind of difficult because you wanted to protect the privacy of the HIV patient and you would say to the other patient, well he has a pneumonia and were treating him and blah blah blah. I know that was a little uncomfortable sometimes, mixing HIV and non-HIV patients. Did I ever fear that I would transmit it to them? No I never felt like I could do that.

**How did the AIDS epidemic affect your view of modern medicine and its limits?**
Looking back, I actually think on one hand they did a pretty good job of diagnosing this. It took several years for them to do this, obviously, but the ability to diagnose that this was a virus and how it was transmitted and everything, I think that was remarkable. I think that the unfortunate part is now that its 30 years later and we still don’t have a vaccine against it and unfortunately people are still contracting it. That’s somewhat frustrating. But I think early on the medical environment did a pretty good job of how that was transmitted. I think it was just frustrating that it was a new illness and nobody knew very much about it. You’re frustrated in that way. But looking back they did do some remarkable things about the different opportunistic infections and how to treat them and how to look for them. But it is more than 30 years and it is a little frustrating that it is still a major issue through the United States and the world.

**Do you feel like AIDS shed light on patient access to medical care?**
I don’t know if that resonates at all with me. The patients down at St. Vincent’s got good care in general. The whole issue of African AIDS is probably a whole different issue, but did it open up more access to different groups? I don’t know. I don’t know if I could answer that. I haven’t really given it any thought.

I always felt like the patients up at St. Vincent’s that I was exposed to. I mentioned before that the drug addicts were treated differently because they treated us differently. They were nasty to us and we could be nasty to them on a certain level. I think that the treatment of the HIV patients were very compassionate. Whether it opened more doors to other groups, I don’t know.

**How did the discovery of HIV alter the approach to the disease?**
Once they knew it was a virus and they were able to develop certain guidelines of certain T-cell counts and who should be started on antiretroviral therapy. I mean, I think that changed everything. There was always some discussion about whether or not to wait until the viral load was a certain level before you start, or if people should be started at any t-cell count. I think early on those were the issues because people would want to be tested and certain people would appear well although they were HIV positive. How do you treat those?

There were certain guidelines back then that would tell you what do with antiretrovirals at a certain T-cell count. So we knew it was a virus and once you knew you could check certain t-cell levels and it came somewhat easier to at least start someone on some sort of prophylactic medication to prevent the full-blown AIDS.

**How did Rock Hudson & Magic Johnson’s public diagnosis affect the epidemic?**
I think that it prompted more people to get tested because obviously if those people could contract it, maybe there were things that I was doing that were not healthy and maybe I am an HIV+ person. SO do think it promoted more testing at that time. Not so much Rock Hudson, but
Magic Johnson in a lot of men – he was a heterosexual guy contracting this – maybe it changed certain practices they were doing and prompted them to get tested. I do think he had a major impact and because he is still alive is a tribute to what medications can do.

How did the approval of AZT change the epidemic?
I think it goes back to testing people and knowing what their t-cell count was. Because you knew you had a drug made a big difference in the people. You could think that you finally could do something to maybe prevent the full-blown AIDS from coming out. Again it was towards the end of that decade. From my own personal perspective, people were gravitating towards HIV doctors and if I was to diagnose somebody with HIV, I would start some of them on AZT. To a fair group of them, I would say to them, “look, I’m a general internist. I’m not an HIV doctor. I do believe you would get better care from these doctors whose whole practices were HIV. Probably in the late 1980’s, I referred many more people. It wasn’t because I didn’t want to deal with HIV. It was because I had other interests and HIV wasn’t my top interest.

Were you familiar with ACT UP?
I’m not that familiar. I remember it and I knew what they stood for, but I didn’t have any dealings with them as I remember.

Did you have a reaction?
Obviously they wanted more rights for these patients and more money to be spent on research. The gay community has a very strong political arm to it. Did I think of them as being so radical that I didn’t like them? I don’t think so. I don’t remember too much about them to be honest with you. It didn’t affect me one way or the other.

Do you think more money was needed for gay research at the time?
I don’t know. I didn’t get that involved in the politics of it. I mean there’s heart disease, there’s cancer, there’s all these other things that everybody needs money for. I mean, Hiv was a pretty significant illness, but I don’t know if more money was needed for it. I wasn’t too involved in it back then. There’s not enough money to go around for everything. Could there have been more cures or better research? I don’t know. I don’t know how to answer that.

What did you think of buyers clubs?
No recollection of any of my patients doing that as I remember.

What were your thoughts on the national agencies’ responses to the epidemic?
Well looking back I think there was a lot of interest and there was a lot of research. Could it have been done faster with more money? I don’t know, but I do think that people did rise to the occasion in the sense that people realized that it was a real epidemic and that it needed to be addressed. I can’t fault any of those agencies in saying you were too lax or you didn’t do enough research. I think that they did as much as they probably could do and I can’t fault them.

What was your response to Reagan’s response?
I’m going to punt on that one because I don’t have any recollection of his response. I wasn’t following Reagan politics about AIDS.
How would you respond to activist critique that the doctors didn’t relay the emergency.
I mean these were cases in San Francisco and New York that were unusual cases, and to criticize
that you didn’t put it together that there was an epidemic. You shouldn’t criticize the doctors and
nurses for that because it was a whole different illness, a whole different disease that hadn’t been
seen before, so I wouldn’t support that criticism at all.

How would you respond to activist critique that the medical community was homophobic,
imogynistic, in clinical trials and in the hospital?
I think the experience now at St Vincent’s may have been different from other parts of the
country because the homosexual community was so prevalent down there. The St. Vincent’s
nurses were just so great as a whole nursing staff. About any patient, they were very
compassionate, so could this in middle America where there is more of a homophobic attitude.
Could that be seen? Sure. But from my experience I didn’t get the sense down at St Vincent’s
hospitals that people - doctors, nurses be homophobic or racist or sexist to be honest with you.
Maybe it’s a unique place, maybe I’m thinking about it with rosy colored glasses or stuff like
that, but I do think the institution with its Christian background and the nuns – they were very
caring. The nuns were very caring for all patients including HIV and homosexual patients.

How do you think working on AIDS patients in the 1980’s affect your career as a doctor?
It always makes you think when somebody has an infectious illness, even down to this day, you
always think, “Could this be HIV?” I never assume that its not. We always question peoples drug
use and sexual habits because you never know when someone presents in your office with a
febrile illness. Could it be HIV? So it makes you delve a little more into those questions, which I
think are reasonable questions to ask.

Did it in any other way affect the way I practice today? I don’t think so. Just in those patients
that have infectious illnesses, I think it has taught me that yes its always a possibility just like
you think now days when you see a patient that is sick and do they have lymes disease? It comes
down to some strange symptoms patients have. You always say umm is it lymes disease? But
afebrile patients who are ill for a while, I think you always have to question, could it be HIV?
Should you ask more questions?

How do you think the epidemic affected NYC?
Unfortunately a lot of talented, creative people died during the epidemic. Did it affect the city
financially? I think the hospitals then were I don’t think financially strapped because of the care
they were giving and the length of time over hospitalizations that these patients had. I think NYC
has been more accepting of different groups. Its kind of an open question. Its interesting, now
that you don’t hear all of that patients who are being treated are living longer and I think the
major thing now about the AIDS thing is that some, especially gay patients, are not practicing
safe sex activities and I think younger kids are getting infected. But I think that’s the unfortunate
thing that there was probably more of an issue of stopping those types of activities and now its
kind of come back a little bit