

*This is an oral history interview with Dr. Christine Grady about the National Institutes of Health's response to AIDS. The interview was conducted on 30 January 1997 in her office in the Clinical Center at the NIH. The interviewers are Dr. Victoria Harden, Director, NIH Historical Office, and Dr. Caroline Hannaway, NIH Historical Consultant.*

Harden: Dr. Grady, we would like to start with your growing up. Where did you grow up, and who influenced your decision to go into nursing?

Grady: I grew up in New Jersey, one of five kids in a very close family that is still very close. It is hard to say who influenced my decision to go into nursing, because nobody else in my family—parents, grandparents, aunts, uncles, nobody like that—is medical or in any way related to health fields. When I was little, I had the usual range of "what I want to be when I grow up" kinds of things. But when I was fairly young, I thought I wanted to be a nurse, and my mother encouraged it the most, even though she was not one herself. She thought nursing was a noble profession and a good thing for me to do. So she encouraged that.

Harden: Tell us about your college experiences. Did you go straight to nursing school?

Grady: Interestingly, I applied to several colleges—I cannot remember the number any more—but only one was a nursing school, and I got early admission. It was Georgetown, and I decided to go there. There was at least one juncture during the course of my four years there that I tried to switch out of nursing and was convinced by the then secretary to the dean not to.

I guess I was finishing my sophomore year when I decided I wanted to go to medical school, and therefore I needed to take some courses that otherwise would not be available to me. This particular woman, who in many respects was the heart of the nursing school, convinced me that I should do both. She said, "Why not do both? You can do it. Just take a few extra credits. Do the hard sciences, keep the nursing. You might be glad you did." So I did.

I finished with a double major, nursing and biology, and I did apply to medical school when I graduated from college. But that first time around, I did not get into medical school anywhere, and I quickly realized, after I started working as a nurse, that I was very happy doing what I was doing. I never did go back and apply to medical school. I was encouraged to work for a year, take a few more courses, and so on, but I never did reapply. In those days, it was much more difficult for women to get into medical school. Also, it was actually—unfortunately, this is true—counted against me that I had a nursing degree.

Harden: Did it? Why was that, in your opinion? The point of view?

Grady: No, it was just the status, for lack of a better word, of nurses. A college degree

was one thing, and I had the double major, but it did not matter. The fact that I had been prepared and trained as a nurse throughout my college years, I think, I was sure of it, counted against me.

Harden: Looking at your curriculum vitae, we could see that you were active in various theoretical issues, such as the rights of the mentally ill, in addition to your bedside nursing responsibilities. How did you develop these kinds of interests?

Grady: Many of those were in my college days. I think some of it came from the orientation that my parents gave me. When we were children, I can remember at young ages going on civil rights marches and things like that, because my parents took us there. We did not know what they were really about, because at the time, although I was older than some of my brothers and sisters, I was not that old. Some of those things did not register directly then, but I think they had an impact later on. So I have always been interested—again, there was my parents' influence—in social issues.

When I got to college—of course, I was a product of the 1960s and 1970s, so some of that was a cultural time situation as well—there were several issues that interested me. I was very interested in women's issues and did many things in college that were related to women's interest groups. Then I became involved in a public interest research group which was just beginning in the early 1970s. It has since evolved into a much more widespread and formalized institution than it was in those days. In those days, it was a very grassroots organization. It was open to any issue. The particular group that I was hooked up with happened to be doing a project on the rights of the mentally ill. So I did not select the topic, I selected the group. Nonetheless, I found it very interesting in terms of what the project was about.

I spent some time during those years at St. Elizabeth's [Hospital] interviewing people, both patients and staff, and I worked with a couple of lawyers who were most interested in issues relating to voluntary and involuntary commitment.

Harden: We are always interested in learning how these early experiences led a person to the position that they have now.

Grady: I did not know much about that one, but I bet it had some influence. I am sure it did.

Harden: But at least it gave you experience in certain areas.

Grady: Yes, absolutely.

Harden: What about your two years in Brazil, working with Project Hope. What led you to that, and what did you learn?

Grady: Again, it was probably the sense of social responsibility that I have already alluded to. I remember as an undergraduate hearing about some of these international health organizations and being very interested in that. I had a sense of our responsibility to the rest of the world, and had actually applied, when I lived in Boston, to both the Peace Corps and Project Hope.

Again, the opportunity arose at a juncture in my life when it made sense to do it. I did not select Brazil. They selected Brazil for me. But it was an incredible experience, both in terms of the health perspective and life experience, living and working there.

Harden: Did you speak Portuguese before you went?

Grady: No, I did not.

Harden: You learned the language while you were there?

Grady: I learned it there. And learned it under fire. I had some classes the first month or so that I was there. But then I was thrown into a hospital situation where I was the only English-speaking person, and I was initially put in charge of a group of clinics. There were, I think, 25 clinics altogether. There were a couple of nurses, but primarily there were nurse's-aides-type people. But I had a staff of maybe 30 people that I was supposed to supervise, so I had to be able to speak to them. I learned very quickly.

I also ended up sharing an apartment with a Brazilian woman and learned a lot from her. She did not speak a word of English. In fact, my parents still talk about calling me up on the phone and hearing this panic at this other end when she would answer and say, "I don't know, I don't know," and get rid of the phone as quickly as she could.

But Brazil was a fabulous experience for a number of reasons. At that point I had had several years of working as a nurse in different situations in the United States and also of teaching nursing, and I had dealt with a lot of what you sometimes think of as crises in the respective jobs that I had. I remember, in fact, very specifically the night that I went to Project Hope for an interview. I had just come off of a day where I ended up doing a double shift because people did not come in. This was in a hospital that was fairly well staffed and had its range of issues, but it was a reasonably well-organized situation.

Then I went for the interview and was given enough information to imagine what Brazil would be like and the lack of resources that I would encounter when I got there. But even then, hearing about it is nothing like experiencing it.

The range of health problems that we were presented with was great. In fact, the large majority of problems were infectious diseases, which was not surprising, but again it was something that you have not thought about very much when you are coming from a hospital in the United States, and some of the areas that I had worked in were quite specialized as well. Often the situation would be complicated by the fact...

The particular hospital where I worked was located on the edge of a city in a very poor state in Brazil, and the majority of the patients came from the interior of the state. Their arrival would be at the end of a five- or six-hour, or sometimes two-day, journey on a bus to this hospital. And that was the first place that they came to, a federally supported hospital that was supposed to service everybody in the state—in the country, really, but in the state.

We were often faced with the problem of physicians who would come in and say, "I am going to see only 10 patients," and there would be 75 to see. Or a physician would see a patient and prescribe a medication, and the hospital pharmacy did not have it, the patient had no money, and that was the end of the treatment. Or situations where, for instance...I can remember a patient that I knew quite well who had leukemia, and in addition to the medications that she could not get, there were often crises where she bled, and there was no blood available for transfusion. Or equipment. A large part of the equipment that we used was equipment that had been donated over the years, some through Project Hope and some through other organizations.

But one story that I have told many times since is about the syringes, which were disposable syringes. We use them once here in the United States and then throw them away. In Brazil they were re-sterilized over and over again. Presumably the sterilization was adequate, but over time the bluntness of the needle made it a whole different ball game. You needed a different degree of strength when you went to give somebody an injection. I remember after coming back to the United States, that in the first injection I gave here after having spent two years there, I almost went right through the person's bone. I just forgot the degree of difficulty of inserting a blunt needle versus that of a sharp needle.

But there were a number of wonderful, eye-opening experiences about being in Brazil. Brazil is unique in the sense that it is a wonderful place—the people are very special and the area was physically one of the most beautiful places I have ever been. But the poverty was also about as severe as any I have seen.

Harden: At the hospital in Brazil, did you get many tropical diseases that were similar to some of the kinds of problems that AIDS patients get today?

Grady: Yes. There was a huge amount of schistosomiasis, which AIDS patients do not

get. But once I came to the NIH and started working in the allergy and infectious disease units, we did have some schistosomiasis patients. The other disease was leishmaniasis, which, again, I had never seen prior to being in Brazil, but have seen here at the NIH since. Those two were quite common.

There was also a lot of Chagas disease, which is pretty much unique to that part of Brazil. There are some other areas in the world that have it. And a large percentage of the infectious diseases were simple things like *Ascaris* and ringworm and things like that.

Harden: Now, it was during this time, if my memory is correct, that AIDS came on the scene. Before we discuss your coming to the NIH, can you comment on when you first heard about AIDS, what you heard, and what you thought about it?

Grady: Yes. I actually did not hear about it in Brazil. I may have read something in the newspaper, but it did not register at the time. I came back—I do not remember the exact date, I guess it was around the end of 1981—and worked for a while on a per diem basis at a number of hospitals, mostly in Boston but also in one in New Jersey near my parents' home; and that is when I first heard about AIDS. There was at least one patient, actually, in the hospital in New Jersey that people thought probably had this disease. And although there was very little understanding of anything, there was fear, certainly, in that particular environment.

Harden: Can you talk more about that? This was in a private hospital? We have not heard much about this in terms of who was afraid. Was it staff, physicians, nurses, everybody? What kinds of concerns did they have?

Grady: I think it was everybody, although I was more tuned into what the nurses were talking about. I was a temporary staff person, so I was not as hooked in as some were. But I do remember two patients in particular, one a young woman and one a young man, who had these unknown ailments, they had lymphadenopathy and fevers. He actually had something else, although I do not remember any more what it was. But there was just this buzz around the nursing station: maybe they have this new disease, do we really want them here, and what are we going to do about taking care of them. Yet, there was no diagnosis or anything. It was very possible that either one of them could have had something entirely different. Just because they had some of the symptoms and their age and a question mark about diagnosis, they were lumped in this category.

Then I remember more vividly a conversation that I had. I had spent some time that summer, right before I came to the NIH, teaching at a governor's school in New Jersey. It was high school students, but gifted high school students who were selected for this program, and there was a faculty of people from a variety of different disciplines. It was a very interesting program, an interesting

experience, and many very intellectual conversations occurred over the course of the month or whatever it was that we were there. This issue of AIDS came up at one meeting. We were sitting around and people were talking about this disease. They were asking, "Wouldn't you be afraid to take care of these people?" Nobody else was a health care professional in this group. I was the only one. At that point I knew that I was coming to the NIH and that I was going to be working in infectious diseases. I guess that at some level I knew there was HIV here, although we did not call it that then. I knew that they were studying this issue here, or they should be. I remember at the time defending this issue by saying that you take care of people because that is your job. You do not worry about what they have. You cannot, or you would not be able to do what you have to do. I was dismissing it pretty offhandedly, probably out of ignorance. I did not have fear, but I probably did not have enough knowledge even to be afraid.

Harden: I want to ask one more question about your background, because we covered this in terms of your motivation. Was your parents' interest in social issues and yours rooted perhaps in religion or rooted in civic activity? Can you pin it down? Was it both of the above?

Grady: I think it was probably not one over the other. Certainly my parents are very devoutly Catholic, and there is some service in the sense of the Catholic religion. But I think it goes beyond that. There is a civic duty. Again, although my father was the orchestrator of much of the activity that I described earlier, I think perhaps the influence in this regard was really my mother. She was more behind the scenes, but always there, always pushing it. Still, to this day, she is very active and does a number of things in the community.

Hannaway: That is good to hear. We want to know about your coming to the NIH, which was in 1983, and you just mentioned that you knew already that you were coming when you were at the governor's school. Can you tell us how it happened that you came to the NIH, and then we will ask you questions about your experiences here.

Grady: We know how people put together their motivations in retrospect. I had a job in 1976, 1977, and 1978, maybe, at Tufts New England Medical Center. I worked there on an NIH-funded clinical study unit—it was a GCRC [General Clinical Research Center]—and I loved that job. Yet—I was just telling the story to someone the other day—we, at that time, had two major categories of studies. One was endocrine and the other was hematology-oncology, and both of them very powerful experiences. But the hem-onc studies were primarily bone marrow transplants for children and for some adults with leukemia or aplastic anemia. These were the early days of bone marrow transplants, where the patient was in what they called the life island, that is, they were completely surrounded by plastic. Everything that we did, we did through double layers of

protection and through this plastic. It was a very elaborate contraption. Most of those people died; almost all of them died.

I can remember at the time being motivated to go back for a master's degree in public health because I could not quite justify in my mind this gross expenditure of resources, time, money, and people's efforts on something which ended up so much a failure. That is why I went to the school for public health and did the public health degree, taught public health, went to Brazil, which I would call public health work, although I was in a hospital, and then came back to the research, which was an interesting cycle.

But when I came back from Brazil to the United States, I had an image in my mind of what I wanted. I said to people that I wanted the perfect job and the perfect place to live. Everybody asked, "Well, what is that?" I explored several possible jobs in New England, which was where I had been previously. I almost accepted one job, which was a research job also, at the Brigham [Brigham and Womens Hospital].

But I was very much attracted to the research aspects of being at the NIH. I knew Washington a little from having gone to Georgetown [University School of Nursing]. So I specifically wanted a job at the NIH, and I called the Nursing Department and basically was told that there was nothing. Then I saw an advertisement for a job at the NIH in the *New York Times* the following Sunday, and I said, "How could this be?" I responded to the advertisement. I became pretty much open to any possibility in terms of a job.

In fact, the job in the advertisement that I responded to and applied for was a job as an educator. When I came and interviewed and met the people, the person who ultimately hired me said, "I want to hire you, but not for that job. I want you for a different job." I said, "Tell me more." I came as what is called a clinical nurse specialist; it the position happened to be in the infectious disease area.

Much of what they wanted me to do initially—I do not know what the right words are—was to advance the level of knowledge of the nursing staff in immunology, because immunology was driving many of these infectious disease studies, and certainly much of the work in that area is and was immunology. So I came to the NIH and immediately, one of the first things I did was to develop a course in immunology, which I taught for several years to the Nursing Department. In fact, somebody asked me this morning, "Why can't you teach that course again?" I said, "My life has taken a little bit of a different direction."

Harden: Let me get you to explain where you learned your immunology, because that is the time when cellular immunology was just...

Grady: Exploding.

Harden: I tried to find materials about cellular immunology at that point, and it was very hard.

Grady: It was very hard. When I took the job, the person who hired me said, "We want you to teach a course in immunology." I said, "I don't know anything about immunology. How can I teach immunology?" She said, "You know as much as anybody else. You find out, and then you teach the rest of the staff."

I took two, maybe three, FAES [Foundation for Advanced Education in the Sciences] courses in immunology, I read many books, and I talked to all the investigators in NIAID [National Institute of Allergy and Infectious Diseases] that were doing intramural immunology. After everything that I read, I would go back and say, "This doesn't quite make sense. Explain it to me." After a time I felt like I knew a little of the basics. As I put the course together, I relied on the people in that institute to help me make sure that the things I was saying were correct. They reviewed materials for me and helped me update things. It was a very supportive group to work with in terms of some of those efforts.

Harden: Let me pin down one more matter here, too. You actually were hired as a nurse. You were paid by the Clinical Center, and the Clinical Center assigned you to the NIAID wings?

Grady: That is right.

Harden: Did you ever move into working for NIAID?

Grady: No.

Harden: It has always been the Clinical Center?

Grady: Yes.

Harden: We have been trying to sort this out with everyone we interview.

Grady: No, I never worked for NIAID. I worked during those years with NIAID because I was assigned to those areas clinically, but I always worked for the Clinical Center, until I went to NINR [National Institute of Nursing Research].

Then, clinically, AIDS was beginning on those units in those days, and it was really only beginning. I mean, there was a handful of patients, but it was clearly...

Harden: Is this 1983 that we are talking about?



Grady: 1983.

Harden: Yes.

Grady: But it was clearly something that was going to grow. That was obvious. And there was much interest on the part of the investigators and a lot of interest and concern on the part of the nurses. It was a natural thing for me to start to learn as much as I could about it as things were being discovered; and that is what I did. It became, over time, the area on which I focused the most attention. In the very beginning, that was not true. I learned as much as I could about it, but I was also learning about Wegener's granulomatosis and the other vasculitis diseases, and some of the allergic diseases that were being seen up there, and these infectious diseases, about which I felt like I had a little bit of an edge on information, since I had seen some of them in their real setting and other people had not.

Hannaway: Could you describe your first involvement with AIDS patients?

Grady: Yes, I think I can. Some of that is a little hazy. Some of the patients that I remember from late 1983 and 1984 were the patients to whom I became the most attached. I learned an incredible amount from them and became very close to some of them. Amazingly, there are two who are still alive and come here, and whom I still try to see whenever they come.

But in those early days, there were a couple of studies that I remember very specifically because of the nature of the studies and because of some of these individual people. One of them was a study of IL-2 [interleukin-2], which, ironically, is still going on, but in those days it was a very different product and there was a very different approach and many problems in terms of the way it was tolerated by people. Even though I was a clinical nurse specialist, I did take a couple of patients as primary patients, and the patients—I cannot remember if I volunteered for them or was assigned to them—were HIV patients on IL-2 protocols.

Harden: You, as a nurse, at that point interfaced with the physicians whose protocols these patients were on?

Grady: The clinical nurse specialist's job is a very interesting job. It is in some respects undefined, and in other respects defined in a way that means it covers a lot of territory. They talk about it as advanced practice, which means you can and do take care of patients, but the primary responsibility that you have is not to have a caseload of patients, but to mentor and oversee the practice of the other members of the nursing staff and bring it to the highest level possible. That is done through modeling, education, working together, hands-on stuff, and

research, to the extent it is possible.

I did take some patients in those days, but I spent a lot of time with the staff. With the investigators, I felt as though much of what I was supposed to do was to help make not only the goals of, but also, what was probably more important, the day-to-day operational aspects of the research understandable to the nursing staff. I also had to facilitate it so that the people would do what they had to do according to the protocol in the way that it got done and was of high quality, but did not take precedence over taking care of the patients. Do you see what I mean? It was somewhat of a balancing act in that regard.

I spent a lot of time reading and interpreting protocols, putting together the tools, testing out equipment, teaching nurses about the studies, developing educational materials for patients about the studies that the nurses could use, and things like that.

Hannaway: What problems would you say came to the fore most quickly? Was it concerns by nurses about safety, either their personal safety or the difficulties of working with patients with this syndrome, and all the range of infections that occurred? How would you describe it?

Grady: Certainly the concern about safety was one that was always there. But I have to say that, in my opinion, the Clinical Center did a much better job of dealing with that than did many other institutions. I had the opportunity at times to talk to nurses in a variety of other institutions—private, around the country, local, both. In some places, safety was a very big problem. In this building, it was not. It was a concern. Everybody was always concerned, legitimately. We did not know what we were dealing with in those early days. But the investigators that we were working with and the hospital epidemiology people were very good about telling us everything they knew and bringing everybody together in a room and saying, "This is what we know, this is what we think. Let's try to work on this together." That gave the nurses confidence that they were not being led down a path of deception, that if anything became known about danger or precautions that should be taken, we would know about it as soon as anybody else did.

I know that a couple of years later, in 1986, there were still concerns. I was thinking about that this morning because we had a conversation upstairs about working with tuberculosis patients, and the nurses' concern about safety is legitimate. In 1986, when I was pregnant and was working in the area, there was still confusion about whether or not it was safe, whether pregnancy was an issue in terms of immunosusceptibility or something like that. At the time, I also remember, again, talking to all the people around and getting the data that was available and being pretty assured, both in my own mind and by the people that I spoke to, that short of a needlestick or something, in being pregnant, I probably

was not at any risk from the HIV. Now there were other disease problems, CMV [cytomegalovirus] and some of the other things that some of the AIDS patients and others had, that may have been more of a problem.

There is a story that I have told many people. We were fairly clear that CMV and pregnancy was—we still know that—and is a problem. There were people who advised me that there were some invasive kinds of procedures that I should avoid doing with the AIDS patients because they were heavy carriers of CMV, and I should use certain precautions, which I did.

Then I remember a patient, whom I took care of very intensively, who had eosinophilia, which is very different, had nothing to do with HIV, and he was dying. We were all over this man—and I was pregnant. Only later, by autopsy, was it discovered that he died of CMV pneumonitis. So we were doing chest tubes, and he was spewing sputum and coughing all over everybody. Those are the things that happen. You cannot predict. You cannot always protect yourself, but I guess I was lucky.

Hannaway: You mentioned the hospital epidemiologist, whom we have interviewed. Did you have much interaction with Dr. [David] Henderson? It sounds as though a clinical nurse specialist would be part of a team...

Grady: Yes, absolutely.

Hannaway: ...working to develop guidelines and procedures.

Grady: We did, for several reasons. David was always very available to the nursing staff—and that was not just our group, and I think the world of the Clinical Center Nursing Department. He was very available, very up-front with information, responsive to any question and honest about what he knew and what he did not.

Harden: This was something he stressed in his interview.

Grady: He was, and he was very good at that. In addition to that general way he was with all the nursing staff and being very sensitive to this particular issue around the hospital, he happened to be located on the 11th floor [of the Clinical Center], which is where we were, and also he often went on rounds with the NIAID group. I and the 11th floor nursing staff had additional access to him and to some of the discussions. Plus we had the HIV investigators up there, the people that were doing...certainly they were not the only ones, but a large part of what was going on in the early 1980s was being done right there, certainly the clinical stuff, and in the NCI [National Cancer Institute]. There would be discussions, some more formal than others, about this.

Harden: Can you talk about some of the major contributions made by the nursing staff?

Grady: Yes. Again, this was an area in which nobody knew anything to start with. As I may have already said, it became clear from my position that it was something that I needed to be very involved in, not only for helping in the local 11 West and 11 East areas, but in terms of being in a place where I had the opportunity to think through what the nursing issues were and to share that with people beyond our local group. Actually, Barbara and I and others worked together in those early days. We would be giving lectures to people in 1985-ish, 1986. We were invited to many places to talk about what it was like to work with AIDS patients.

Harden: Outside the NIH?

Grady: Yes.

Harden: Around the country, or mostly locally?

Grady: Some of each. In about 1985, I think it was, there was a nurse in the NCI, Joan Jacob, who also worked with us a lot on some of these issues. She spoke to a group, and I do not remember their name any more. It was a Baltimore-based organization that basically put together educational programs for nurses and sold them to places around the country. She got us hooked into this group. It was primarily she and I in 1985—although I think Barbara probably did some of them, or maybe did some later—who gave these all-day seminars to groups of nurses all around the country. I remember going to Detroit, Dallas, somewhere else in the Midwest, like Dayton, Ohio, or someplace like that. I went to at least five or six different cities around the country to give this canned program that we had put together, a day-long seminar, which basically went through what we knew about the epidemiology of AIDS, what we knew about the clinical manifestations of these patients, and what we knew about treatment, which at that point was virtually nothing. There was a large section on nursing care, what kinds of nursing care were appropriate, what kinds of nursing diagnoses made sense. Then there was a large section on the issue of fear and contagiousness.

Harden: What did you hear from the people you were speaking to? Was it different in different places, or were there common themes?

Grady: It was a little different in different places. Certainly there were always people who were interested in how to do it better. "How do we deal with this? Anything you know that can help us take care of these patients, we want to know." It was always usually the minority, though, somebody in the group or a couple of people in the group, at least, who said, "It is just too dangerous. Why should I put myself at jeopardy, and my family?" "No matter what you tell me, I don't believe you. It's just not worth the risk," and sometimes even more

damning statements than that, but basically that was the sentiment.

Harden: Did you feel obligated in your role as a teacher to argue the case with people who took such a position, or were they just allowed to express their opinion?

Grady: I always argued the case. But there was always a point at which I gave up. Some people you can talk to and some people you cannot. After a while I would begin to be able to figure who they were, or I thought I could.

Hannaway: You could differentiate between them.

Grady: Yes.

Harden: Are there any procedures or policies that specifically stick out in your mind in the 1983 to 1986-1987 period that you thought were either very good or not so good in the way that the staff at the NIH dealt with AIDS patients?

Grady: That was a critical time in terms of being the time when the virus was actually discovered, and that confirmed what many people thought, that it was an infection of some sort. Even at that point, there was a fair amount of epidemiological evidence that the modes of transmission were limited. I think, in those days, there were changes in how we did precautions and things like that. But most of what I remember was confirmation of what we were already doing, to tell you the truth. There was a sense that we were on the right track even though we do not have all the information.

When you had asked before about contributing policy, contributions to nursing, or things that nursing did, I think the other thing that we were able to do here at the NIH that was helpful to people in those days, besides present lectures and so on, was to put together some publications. Some of them were informal "this is what we do here" kind of material that we would send out to anybody that asked—care plans and so on—and others were real publications. Barbara did some and so did Joan Jacob and I. There were others within the Nursing Department. Debbie Trivet in the ICU [Intensive Care Unit] was involved; Sue Simmons from Mental Health [National Institute of Mental Health]. There were people around who all had their areas. We all worked together, I believe, very nicely in terms of thinking through what made sense and trying to figure out how to make that available to as many people as possible.

Harden: Was there a strong sense that you were leading the nation, that what you were writing was going to get disseminated around the country?

Grady: I am not sure that there was a strong sense. There was some sense of, yes, we have to tell everybody what we know because we know more than they do. I can remember actually—I am sure others have echoed this—that sometimes people

would call us and say, "Send me the written materials on such-and-such," and we did not have any. I mean, we would have what we did. We would know it. We did not have the time—we were pretty busy—to write it down into a formal procedure or policy, or even a "this is how it should be done" kind of article. We did not always have something in writing. But when we did, we let it be known.

Hannaway: Would you see nursing journals as the primary outlet for publications to inform the nursing profession?

Grady: Yes.

Harden: In 1989, you published an article in *Cancer Nursing* about the impact of AIDS on the nursing profession. I notice...I can quote this to you. I wrote it down primarily because I saw it in many of your articles, the same ideas that you had obviously dealt with this: "AIDS has confronted us with groups of patients whose lifestyles we may not know much about, may not understand, and of which we may disapprove. Each nurse must examine his or her own attitudes about and comfort with issues of sexuality, homosexuality, substance abuse, debilitating illness, and death, and each nurse must attempt to come to peace with these issues before being faced with a patient or a significant other who needs support and wants to discuss his life."

Now, was it the whole of your experience that inspired this statement, or were there particular things that inspired you to write this?

Grady: I think both. I think the reason I believe that is—although there was the issue that I have already described, that people were afraid of the contagiousness—that was not the whole story. I mean, some of them were, but there was also this, "I do not even want to hear about it because I do not like these people," and some people were very blatant about it. They were happy to say, "I don't like those people, I don't want to take care of them, they deserve what they got, and I am not risking my life to take care of them."

Harden: Did you hear that much at the NIH?

Grady: No. I do not think I ever heard it here. But I heard it a lot everywhere else, outside. I remember one person saying to me one time at a talk somewhere, "You could say anything you want. You don't take care of patients. You don't know what it feels like." And I would say, "Sorry, but I do take care of patients and I do know what it feels like." I think the reality is that those things have not entirely gone away. There are people who do not like homosexuals. There are people who do not like substance abusers as a category. They do not even think about the individual person. It is just, "I don't like them. They shouldn't do that. Why should I take care of them?" And it is not just health care workers. It is all

kinds of people, patients in the next room.

I think that the real truth—and I am glad I said it in that article—is that in the health care professions, we have not—maybe there was not a reason to, but maybe there was—spent enough time understanding how much a person's life habits are important in terms of not only taking care of them now, but just the whole understanding of how they got here and where they are going after this. We have an episode of taking care of them in the hospital. To understand a little about what life as a homosexual is like, who now is afflicted with this disease, and to put that in the context of, "I can't tell anybody that I'm a homosexual. Even my mother doesn't know I'm a homosexual. How can I tell her that I'm sick?" Those things create issues that, as a health care provider, we need to be able to help people with. If we cannot accept that that is part of what makes sense in that context, then we cannot help them.

Harden: Now, what you are saying is the rhetoric is different when you talk with a nurse than when you talk with a physician. This is apparently something that is more common with nurses, to care more about this more simply trying to solve a problem. Would you comment on other differences in how nurses and physicians work with and think about the patients.

Grady: I think they are vastly different. I think some of it is just logistics. When you are a nurse, you are with the person for a lot longer, especially when they are sick and in the hospital. You are with them, at least during your entire shift, in and out, maybe, because there are other patients and things to do, but you are basically there for the eight hours. And you are with them in some very intimate ways. You have to bathe them, you have to help them to the bathroom, you have to feed them, you have to clean them up. I mean, there are things that, relating to another individual, you do not do that unless you are in this kind of special relationship. Even though physicians sometimes do that, and they certainly are in very intimate situations with patients in some ways, it is less often than it is with the nurse. The nurse does it all the time. So you get this sort of image of vulnerability and almost nakedness, if you will, of the patient that you are exposed to, that you know this person at a level that many people do not. It is different from person to person, but they sometimes look to you to understand something about them as a whole person and to be able to help with whatever you can do in your limited context, to put that into the sense of who they are. I have to say, I learned that eloquently from some people that had AIDS that I took care of, because they would say in the beginning, they would... I would talk to them about, "What do you want nurses to know? What do you want nurses to think about when they take care of you?" They would say, "The most important thing that you can do is not to judge me. I am me. I am not some statistic, a homosexual with *Pneumocystis pneumonia*. Sure, I happen to be homosexual, I happen to have *Pneumocystis*, but that is just things about me. I am me. I have got my thoughts, my feelings, my experiences, my life, and all

those are important to how I am dealing with this, how I am accepting or not accepting treatment, how I am reacting to treatment, what I am going to do when I get out of here, those kinds of things.”

There were several patients along the way who were able to express that in ways that I cannot even do justice to, but very eloquently and very convincingly, that you have to... I am a little bit of an idealist, and so I am of the opinion that health professionals in every profession should not forget that to the extent possible.

Hannaway: The person who is sick there.

Grady: Yes. To the extent that you can put yourself in their shoes, you are going to be more helpful to them, more sympathetic to their plight, if you will. Now, you cannot put yourself in their shoes all the way. There is some point at which you do not want to all the way, because you have to keep some semblance of separateness in order to be able to function. But to the extent that you can do that in a healthy way, I think it helps. It helps the quality of your helping, if you will.

Harden: I want to follow up with two more tough questions now. As a nurse, you are bound to have had obnoxious patients, both AIDS patients and non-AIDS patients. And we have heard from other people, I mean, AIDS patients are human. Some are going to be obnoxious, some are going to be nice. How does that affect the quality of your care? Then I am going to come up with a second question when you finish here. What is your reaction, and what did you see? How was the behavior of people with AIDS who were sick?

Grady: Very variable. Some were models of courageousness and strength and worried about everybody around them, and others were a pain in the ass, and that is the way it is. I mean, some people are that way, and some of them have good reasons.

I think one of the things that I believe and that I have said to people is that, just because you are a nurse and you are responsible for taking care of ten people, you do not have to like all ten of them, and you cannot. There are some people you just will not like. The important thing, for my mind, is that you do not not like them before you have met them, which in this case sometimes happens. You learn, before you even come to work, you know there is somebody with AIDS there, or before you ever get the first patient with AIDS, you know you are not going to like them because they are gay or they are shooting drugs, and you do not like that. So you do not like them. I do not think that is legitimate. You cannot be prejudiced in this profession. Some people are. But you should not be prejudiced in this profession because you have to deal with individuals as individuals.



Then the second thing is, that even if you do not like somebody, if they are very difficult and you have tried, there are certain things that you still must do. Certainly the minimum of giving them their medications and making sure they are clean and taking care of them in that way, those are all minimal things. But in addition, I think you must try to, what is the way to say this, give them another chance, or something like that. You have to keep trying. You have to keep talking to them. Now, if they will not talk to you or if they will not... You know, at some point, with some patients, it is you, it is not general. And then you can trade. You do not take care of that patient anymore. Somebody else does. And that should happen when it needs to happen.

But there are some people that are just difficult for everybody. Nobody wants to take care of them. They do not like anybody, and they are going to give everybody a hard time. Then, the important thing is to talk about it as a group and to figure out the most comprehensive strategy, if you will, that does not make that person be neglected. And whether that is little doses for everybody, or if some people who can take it more than others, there are different strategies. But you have got to figure it out, because the tendency with people like that is just to stay away from them.

Harden: Now, let us go to the other side of this coin. Many people outside the NIH, and some people inside the NIH, too, have differed in their opinions as to how the public health and research leadership should have responded. A number of people have said AIDS should have been treated more like syphilis and gonorrhea: the privacy right should not have been so rigidly respected, we should have done contact tracing, yet this was not the case. And the people who made that decision have been attacked. Have you seen or heard much of this, and do you have an opinion on it?

Grady: Certainly I have thought about it a lot, and I would guess, if I had to think through it a little bit, that my opinion may have changed over time. I think that it was issues like that that got me interested in ethics, to tell you the truth. Those are the kinds of discussions that we had early on, in addition to some that we have alluded to, that got me thinking about, how do you systematically approach some of these things and make sense out of them.

In response to that particular situation, in some respects it made sense that if there was a public health model that worked, we should apply it. But I think that there was enough, from my understanding even back then, of a question mark about whether it worked. First of all, do you just do something because it is been done, or do you stop and say, "Is this an analogous situation? Is the model that we have had in place before effective, and, therefore, should we apply it to this situation?" I think that there were enough questions, at least from the people that I heard discuss it, about the middle, primarily, that there was a

door through which they were able to say, “Let us stop and think if we should not respect rights first, and maybe this is not the solution to protecting other people, because it will not work.”

I have written about and spoken about confidentiality in this context quite a bit, and I still am not absolutely crystal clear on what I think is the right way to go. But I do believe that, as it became clear that there were people at risk by not having the information that I had, or that somebody had, and you could identify who those people were, and you had tried everything you could to have them informed in the most logical way, which is by the person who is putting them at risk, and failed, then there are times when it is legitimate to inform them. But that is really a case-by-case rather than a blanket policy that you inform everybody that this person comes into contact with. The consequences of informing in a more lax way were so devastating, in some cases, that it did not seem to be supportive. Sure you could say public health is more than individual rights. In the abstract, I would probably agree with that. But in this particular instance of that, were you really going to protect public health? Questionable. And what were the consequences of overriding somebody’s rights in this regard? They were sometimes quite devastating, including violence. So, it is a dicey situation.

Hannaway: It is. Just to come back to the nursing before we move on to some of your larger activities in the larger world, let us say, in the article that Vicky referred to earlier, you wrote that the multiple medical problems suffered by AIDS patients required an average of 28 percent more nursing time than for non-AIDS patients. Could you tell us a little about how the Clinical Center addressed this demand for nursing time? We are interested a little more in the description of organizational changes or these sorts of things.

Grady: That number I quoted is from another study, I believe. It was not a study that was done here. But it was apparent in the beginning that the clinical care of patients at the end stage of HIV disease was quite complicated, most of the time because they had multiple infections ongoing, any one of which would have been complicated in terms of symptoms. And the treatments have evolved over time, so in the early days it was not so much that the treatments were complicated, because there were not so many. Now that is a big issue. But the time and energy that it took to take care of somebody adequately at an end-stage disease... Unlike today, we have mostly ambulatory patients. We see a lot of patients in the clinic. There are some that are terminally ill, but in the early days we saw a lot more, and many patients died here—not so much anymore—with AIDS. Multi-system failure is really what it was. And yet you see that in other diseases, but many times you see that in an intensive care unit and not on a regular unit. We were seeing multi-system failure after multi-system failure, and it was very labor-intensive.

Now you asked about organizational changes at the NIH. The NIH, the Clinical Center is unique in this way anyway. We have more personnel per bed than probably anywhere in the world. That is because research is also labor-intensive. So, although there was clearly a recognition that in order to take care of some of the patients from some of these protocols, we might need more nursing staff, we were already pretty well staffed. And so I think there were, there have been, minor modifications in terms of FTEs [full-time equivalents] in areas that have more HIV versus less, for nursing staff anyway. I do not know about anything else. Starting in 1986-ish, a lot of the effort, NIAID effort anyway, moved to outpatient, and there was a clinic built up over time, an HIV outpatient clinic, which I think is a wonderful model of how nursing care can and should be delivered. But in terms of really ramping up the number of nurses in the inpatient area, maybe a few, but not overwhelming changes, no.

Hannaway: What about space and location? Barbara Baird described having a cart on which she kept everything at the beginning, and how she was in other people's offices on a temporary basis or that it was...

Grady: Because she did not have an office.

Hannaway: Yes. But I was wondering in terms of space allocation, these other sorts of debates that go on in hospitals, for one disease versus another and...

Gray: Well, I might be wrong, but I think that those... Barbara probably has a more poignant story than I do on this, because I had an office from the day I arrived, although it changed every six months and I was sometimes getting kicked out before I even knew I was in.

I think some of that came with new kinds of categories of positions. Barbara added responsibilities and so was put in a category, if that is the right word, different from one that had existed before. So there was not an office for her. I mean, there was not a title for her at first. Those things evolved over time. So she was in a unique situation. But there were not too many people like her. She was unique in the early days in terms of what she did, and she was identified as such because she was very capable, but also very interested, and so she took on this role and developed it and built something out of her original position as a staff nurse.

Harden: But were you the only clinical nurse specialist dealing with the AIDS, so to speak?

Grady: Yes, in the NIAID areas. There were people in NCI, but most of the clinical specialists in those days were inpatient, and the NCI had very few AIDS inpatients in the early to mid-1980s. They had some, but not a huge number. So there were some clinical specialists up there who dealt with...

Harden: So you were learning what to do and teaching other people what to do, and it was all happening all at once.

Grady: Mm-hmm.

Harden: Again, as Caroline was saying, before we make the transition into more recent times and new things you have done, I would just like to ask a few questions with regard to your personal life. You have already spoken about the difficulty when you were pregnant the first time. You have been pregnant three times, have you not?

Grady: Yes.

Harden: You have three children. And you nursed AIDS patients who were in the hospital the whole time. Do you ever feel like AIDS has taken over your entire life? We have heard that some people have experienced difficulties from friends and family who are not sure they really want to shake your hand. Have you experienced any of this?

Grady: Sure, I have. I have the added complication of having met and married [Dr. Anthony] Tony [Fauci] while he was here, which had nothing to do with AIDS at the time. I met him here over the bed of a patient who happened to be from Brazil. I was called in as a translator because this man wanted to go home, and they were afraid to let him go home because the guy had vasculitis. His vasculitis was not in great control. And so they said, "Could you come translate for Dr. Fauci?" whom I had not met, the inimitable Dr. Fauci everybody was afraid of. When he came in, I thought, "What are they so afraid of him for? He is not so scary."

But it is actually a great story because Tony, in his very serious way that he can be, said, "Make sure that you do your dressings every day and sit with your leg up," and I forget all the details. But I translated that to the patient, and the patient said, "You are kidding. I am so sick of being in this hospital. I am going to go home, I am going to dance all night, I am going to go to the beach, I am going to do this." So I think to myself, "How am I going to do this?" So I turned around to Tony and said, "He said he would do exactly as you said." I kept a straight face all the time.

But because of Tony and his work and his involvement, obviously, probably my life has more AIDS in it than it might have otherwise. I mean, if I had just worked here and had gone home to a situation that had nothing to do with it, I might have separated them in different ways than I have done. Although people used to ask us, "Is that all you ever talk about at home?" and the answer is no. In fact, I think we have been quite good about separating our life from our work,

although probably much more for Tony than for me, his life is his work in most respects.

Harden: He said to us, when we interviewed him, that both of you had dedicated your life to this; it was here, you were both involved with it. So you are bound to share these feelings. But I think it is very hard for any NIH couple—I am a part of an NIH couple—to get away from it all. Yet you do live in a larger community, and you have children—not only have them, but they are going to school, and you are dealing with all this. Have they come home with any stories about...wondering about their parents working with AIDS, this kind of thing?

Grady: Not so many stories, but my eldest, who is only 10, has asked a lot of questions over the years, such as “How do you get AIDS? What is it? What are you trying to do, Daddy? What do you do, Mom?” those kind of questions. And only recently, actually, she has had more people at school ask her, because they see Tony on television and they put her together with him. But I do not think the younger kids have much of a sense of it at all yet. Yes, they will over time.

Hannaway: I agree. When your father is on the “Jim Lehrer Hour,” as he was on Tuesday night, was it... And “CBS News” on Monday.

Grady: Right.

Hannaway: What we would like to turn to now is some of your activities on commissions and so on beyond the NIH. First, would you discuss some of your activities as a staff member on the Presidential Commission on the HIV epidemic? And how would you assess the contributions of this Commission?

Grady: I was called at home one afternoon—I think it was a Sunday—by the head of the Nursing Department, who said she had received a call from somebody downtown, at DHHS [Department of Health and Human Services], asking about a detail, whether I could be detailed down to work at the Commission. I thought, “Gee, that is intriguing. I wonder what that is all about.” So I said, “Sure, I’ll try that,” thinking it would be very short term. And it was short term, but it ended up being longer than the original arrangement was.

It was an immersion in a whole different way of looking at this problem that I had not experienced before. I mean, some of the things that were really funny, in a way. When I first came, there was a physician there, and he and I worked together, and our area was to look at delivery of care, some of the more specific medical care issues. At one point they asked me, “Find out what you need to know about hospice care for AIDS patients.” So what I was used to, in writing papers and articles, is that you do a review of the literature and you put it all together, and you end up with a 20-page or so package of information. And O was told no. I mean, “You cannot review the literature. You find out what you

can. By tomorrow, I want a one, at most, one-and-a-half, page synopsis of hospice care for AIDS patients,” which had to start with “what is a hospice” and end with “how much money are we spending in the United States on hospice care for AIDS patients?” and every other problem in between.

Hannaway: Go off the page.

Grady: That was a culture shock for me. But I quickly discovered that many of the people that worked at the Commission, staff members, had been congressional aides, and that is the way they worked. They deal with the problem, a comprehensive problem, boil it down into an understandable synopsis that hopefully covers the important things that somebody who has very little time can read and understand the important issues about. So I learned how to do that very quickly, and then we did lots of those over the time. After a while...

Actually, there were several other people. When I first went, there was another nurse from the Navy, and there was a social worker—from HCFA [Health Care Finance Administration], I believe, or maybe HRSA [Health Resources and Services Administration]—also detailed there, the two of them, the three of us. And then this physician was a Hopkins physician. And after maybe a month or two at the most, all of them left, and it was just me in terms of the health care aspects of this issue.

There were some very well-educated members of the staff in terms of some of the issues, but their backgrounds were primarily congressional rather than health care.

But, again, it opened up not only the world of how these things work, like commissions and Congress, but a whole other dimension in terms of how you look at some of these issues. I was used to thinking about how you take care of an individual and maybe how you put together a sense of, after having taken care of 100 individuals, what works and what does not, what is important and what is not. But now I am coming at it from the angle of do these people need hospice care, is hospice appropriate, who is going to pay for it, how do you justify it, and what do we have to do to strengthen what exists in terms of hospice organizations to be able to provide it, and what are the barriers? That was a really different angle on some of these situations, but immensely interesting.

I think you had asked, does the Commission make a difference? I do think they did. They were beleaguered by a lot of early political battles, and political battles right to the end, some members who did not agree with the final recommendations. But they took on the topic in a very comprehensive way and, I think, came out with some very reasonable recommendations about next steps.

People have criticized it since. You know, maybe they did not go far enough or maybe nobody paid enough attention to their recommendations. There is probably truth to all of that. But they did do a lot, and a lot of people, in subsequent years, relied on both their summaries and their recommendations in terms of where to go.

Hannaway: So another activity you had at about the same time was the Task Force on AIDS of the D.C. Board of Education.

Grady: Yes. That was a very interesting process also. And through both of these experiences, I met a number of people, some of whom have continued to be influential in this area or in other areas.

Hannaway: How did you get into the latter? You were not detailed to that.

Grady: No, I was not detailed. I do not remember, actually, how I got there. But it was, again, they needed somebody, and somebody said, "Get her to do it."

Hannaway: "Why don't you ask her?"

Grady: I did it. I think it was through here. I live in D.C., but I do not think it was a D.C. connection. But perhaps they thought it was a good idea because I was also a resident of D.C. And it was definitely because...the nursing part was what they were interested in, in my opinion.

Hannaway: But it was not an NIH outreach effort.

Grady: No, I do not believe it was. I do not remember. But I was the only nurse in that group.

Harden: Were you involved in addressing the issue of distribution of condoms in the schools, or sex education, or all of that?

Grady: No. The major issues were, what do you do with children or faculty or staff who have HIV? Do you let them stay there? Who do you tell? How many people have to know? What kinds of precautions should you put into the local school? Do you give everybody gloves? Do you tell them only to use gloves with this kid or do you use gloves with everybody? Those kinds of issues are what we dealt with.

And it was very interesting because it was not just kids in school. The D.C. Board of Education also has some residential facilities for kids with chronic problems and mental retardation that have wide—not wide, but prevalent levels of hepatitis and other things, so that... And kids that needed day care and hands-on care and... So it was more complicated than just kids in school. But those

were the issues. We did not deal with condoms or sex education at all on that task force.

Harden: Now, from January 1987 to September 1987, you served on the Intragovernmental Task Force on AIDS Health Care Delivery for the Public Health Service. Tell us what that group did.

Grady: What was his name? There was a guy, a very good guy. I cannot think of his name now. He was from Utah. He is a physician. He came to Washington as a member of Orin Hatch's staff, and then was recruited as the director of HRSA around that time. He put together this task force, and it was members of all the federal government agencies.

We dealt with a lot of different issues, but I think some of them were system-wide, what the government, what the different agencies, should do or should have as priorities in terms of this issue.

And I had not thought about that report in a long time, and I could not probably even tell you what was in it, or I would have it on my shelf somewhere.

Harden: You were coming from the NIH, from a research point of view. But you are also a nurse, so you know a lot about health care delivery. I was really interested in whether this gave you a unique perspective in this particular body, and if you recall whether the other PHS [Public Health Service] representatives might have come at it from a different way.

Grady: Absolutely, absolutely. I do not know for sure, but I always thought in those days that what they were after, from my perspective, was my nursing perspective rather than the research perspective. But I could be wrong about that. But that is always the way I approached it.

Harden: How was that group, if you can recall, different from the Public Health Service AIDS Work Group on Patient Care and Health Care Delivery, which you were also on at the same time?

Grady: The Intragovernmental Task Force was interested in a whole range of issues, and if I recall correctly, from the perspective of what should the respective agencies be doing. Whereas the other task force was more interested in specific issues related to patient care, which were more generic in some respects, but crossed agencies in other ways and had nothing to do with some agencies. That was a group that did not go as far in terms of a product. The Intragovernmental Task Force came out with a report. It was a time-limited entity which had a goal and a report, and then ended. The other one was supposed to be ongoing, but then fizzled out after a while. And we never had a product, so to speak. We just had ongoing discussions. I think perhaps it got incorporated into some



other committees. I do not know what happened to it, but it fizzled at some point.

Hannaway: From 1989 to 1993, you assisted in the design and conduct of intramural research on symptoms of HIV- infected adults, and this was during the early years of the National Center for Nursing Research [NCNR], which was initially set up in 1986 and then became the NINR in 1993, and comprised a portion of the intramural program of that center. Could you discuss your activities in this connection?

Grady: When the NCNR started, the first director wanted the NCNR to look like the other institutes in terms of having both an extramural program and an intramural program. She was exploring in 1989-1990 the possibility of creating an intramural program and decided to put a relatively small collaborative program out of her office in HIV and hired a person to do that. In the first few months that she was here, that person, Mary Roca, spent a lot of time with me, because I was in the clinic and I knew a lot not only about the clinic operations, but also about the HIV clinical area from a nursing perspective. We spent hours discussing possible research questions and priorities, how it would work in this environment, and so on.

One day she said to me, "How would you like to come work for me?" It was right at the time when my second child was born, and she made it even more attractive by saying I could work part time, so I did it. I went to work for her in helping her set up the program and in putting together the first couple of studies.

We did two major studies in those days. One was looking at nutritional aspects, because it was my and many other people's observation that nutritional problems were a big problem in AIDS. What was not known at the time was why. When did these things start to happen, what happened first, and was there a way to intervene to prevent them or to at least minimize them? So we put together a pretty complicated, longitudinal study of several cohorts of patients that were being seen here and followed them by documenting their nutritional status, their immune status, and clinical status over time to determine when and how these things changed.

Then the second study came out of, again, a clinical observation. We had been doing studies in the clinic with AZT from early on, and were among the first groups to notice that some people who had been taking AZT for a long period of time developed these rather profound muscle weaknesses. We wanted to understand that phenomenon better, so we put together a protocol to study people who had clinically determined myopathy and follow them prospectively to see how it impacted on both their muscle strength, but also other symptoms and functional abilities. Those are the two main studies that Mary was the principal investigator for, and I helped her do them.

Then in 1994, she left, and I was supposed to take over some of her work and also justify my existence by writing some more. So I put together another protocol, because one of the issues that I had been concerned about from the beginning of this disease, but also in many other diseases, is fatigue. It is a very prevalent symptom, one for which nobody knows what the heck to do about and, for some people, it is the most annoying symptom that they have. It ruins their life because they cannot do anything.

Hannaway: They have no energy to do anything.

Grady: No energy. So I put together, again, a small descriptive study of fatigue and had, because of the population available to me here, an interesting model, I thought, in terms of IL-2 patients, because IL-2, among other things, in most people causes a very debilitating fatigue. But that is transient. They start their IL-2, and by the next day they are flat. They cannot do much. But the day the IL-2 is stopped, within 24 hours they feel pretty good. That fatigue phenomenon was of interest.

But the other thing was that, as I was talking to patients, they would say, “The mouth sores go away pretty quickly, the fluid retention goes away,” some of the other things that IL-2 causes, “but it takes me a long time to get my energy back.” I wanted to see both how this worked during the IL-2, but also what happened in between cycles and whether or not it ever came back. So that was what that study was about.

Harden: Let us see if we can move into your current work in bioethics. We have touched on a number of issues already that pulled you in this direction, but how did you actually decide to go and get a degree in it? We also noted that you were a member of the Bioethics Liaison Group during this period also. Can you go back and bring us up to date on the bioethics the way we went through nursing?

Grady: Again, it would be hard to pinpoint when I first started to be interested in things that I would now call bioethics that I may not have always called, but certainly I was. When [Dr.] John Fletcher was here in—well, when I first came, he was here. He was doing some things that I found very interesting, and occasionally I would volunteer to work with him on such and such a project. When this Bioethics Liaison Group was created, the Nursing Department, I think, had two slots, and I lobbied hard to get one of them, which I did, though not immediately. Then when I was thinking about going back to school, John was a major influence in that regard in terms of studying ethics, because I was not sure that is what I wanted to study. What I ended up with was a degree in philosophy, and philosophy to me seemed sort of fluffy. I hate to say that, but it was true.....

Harden: In a sense.

Grady: Right.

Harden: Remote, yes. Fluffy, I would never.

Grady: Well, maybe remote is a better word. I mean, I was very concrete. My education had been very concrete. I was doing these things, and I thought perhaps it might have been better for me to do public policy or something like that, because I was definitely interested in the public policy aspects of some of this, and those were the bigger-picture questions about health care issues. But the more I thought about it and the more I looked at programs, the more philosophy started to appeal to me. And fluffy would not be the word I would use today to describe it.

Hannaway: That was your initial reaction.

Grady: Intense is probably a better word. So I decided to get a degree. Certainly, Georgetown has a very good philosophy department, but also a reputation for the health care-related ethical questions that I was definitely interested in, and I had the added advantage of being close, so it seemed like a good place to try to go. I was happy and lucky to get in.

It was an interesting time, because I was studying philosophy, I was still working here at the Commission during those years, too, and I was having children all at the same time. There was a lot going on.

Harden: Yes.

Grady: All of which, in many ways fed into each other. There were certainly issues that I was dealing with clinically and in the Commission that were ethical issues. They were blatantly so in some cases and not so blatantly so in others. And having children—I do not know if either or both of you have children—gave life a different dimension and a different perspective than I had had previously. I think that added to my appreciation of philosophy, to tell you the truth. There were moments when I was thinking, “What am I doing trying to do all this?” and I have some great stories about going into labor in the middle of metaphysics class. But in other ways, it all sort of came together.

As I was studying philosophy, of course, I continued to be interested in the things I was doing clinically. When I first started to get ready to do a dissertation, my topic was not going to be anything to do with HIV. I was interested in studying something related to something I had seen here, the participation of women in research and whether that was an injustice issue or some other issue; I had talked to several people in terms of trying to recruit a

committee and was not getting too far. There were some people who were not that interested and other people thought it was not philosophical enough. There were lots of things going on.

Then I went to [Dr.] Leroy Walters, who ultimately was my mentor, and had a long conversation with him one day about, “What should I do?” And he said, “Maybe you should start thinking about a different topic and think about something that is related to your work.” I said, “Well, there are about 200 that I could think of,” issues that I thought of in my work that might be... And he said, “Tell me about them.” I said, “All of them?” He said, “Yes. Tell me about them.” So I started to talk about all these things that I had thought about or seen in clinical medicine, and when I started to talk about vaccines, he said the pitch or something, the enthusiasm changed. He said, “That is the one. That is the one you have got to do.”

And that was a clinical thing. It started in the clinic, we did the first Phase I HIV vaccine study, which was, at the time, leading-edge science. It was very exciting in that regard. But I know that I remember many a day sitting in the clinic with the other nurses and some of the investigators and saying, “Who in their right mind would ever volunteer for this thing?” “How are we ever going to do this study?” We put together in the clinic a small study to study the motivations of people who were participating in this vaccine study, because it seemed like brand-new, first-time, Phase I, and the four pages of theoretical risks were just unbelievable. So that was one thing.

Then, at the Commission, thinking and talking about the importance of developing a vaccine and thinking about, if we have trouble getting people into this early Phase I study, or I think we should, what happens when you get to the stage of trying to figure out if it works? How do you do that? So I started getting interested in that whole subject, and the rest turned out to be my dissertation, which other people liked enough, too, to publish.

Harden: It certainly addresses the most up-to-date question with regard to AIDS. The therapies are nice, but they are expensive and they are not going to solve the problem in the Third World.

Grady: Right.

Harden: And the vaccine has to be pursued. So I would expect that your book has probably generated a lot of interest for people working in that area.

Grady: It has, although it is interesting. I think there is more interest today in late 1996, early 1997, than there was in 1993, when I actually finished that, 1994.

Harden: That is the way you sell books.

Grady: Yes.

Harden: All right. So we have brought you virtually up to where you are now. You are now responsible for planning and management of the bioethics program, which has grown considerably since John Fletcher was the only bioethicist at the NIH, is my recollection.

Grady: That is right.

Harden: But a part of your responsibility involves participation in the Institutional Review Board of clinical protocols. Could you comment on how your training as a nurse and as a bioethicist informs the way you approach that duty?

Grady: That duty. Yes, I can. From early on in studying ethics, but probably predating my study of ethics, I have been interested in the ethics of research, I think from being here, from watching it, from thinking about what it is. So I spent a fair amount of time studying that in terms of what has been done and written in the past, which gives me, perhaps, an advantage in the IRB [Institutional Review Board] work in the sense that I have thought about some of the issues of research more than a lot of people on the IRBs have. I have had the opportunity to read about them, talk about them, write about them, and so on.

I think in all that I have done and hope to do in ethics, the fact that I am a nurse gives me a distinct advantage in that I can understand the other side, if you will. From the perspective of designing research and putting together a study that answers an important question, and being clear about methods and, putting protection in for human subjects, in some respects that is also abstract even though some of the people who do it are in contact with the patients as well. But some people on the IRBs are not. Yet there are certainly things that you need to look at in the abstract. But then to be able to envision in a more real way what the person at the other end who is participating in this research is experiencing I think gives me an advantage. I think the perspective that I contribute at IRB meetings and in a lot of other things that I do is a blend of those two.

Harden: Are you the first person with training as a nurse that has sat on the Clinical Center IRB?

Grady: Well, the Clinical Center does not have an IRB, so it is the other NIH IRBs, for each institute.

Grady: Interestingly, I have actually done this through the Bioethics Department before. And there have been at least one or two other nurses, in the time that I am aware of, anyway.

Hannaway: I actually had a follow-up question to something that you remarked on earlier. You mentioned the clinical trials for AZT. Were you involved with the patients who were part of those trials as well as the ones for the vaccine?

Grady: Yes.

Hannaway: Can you just tell us a little about that, because there has been a lot of discussion about AZT and how when it was in the Phase II trial, the decision was made to alter the nature of the trial, so to speak. But I was interested in the Phase I.

Grady: Yes, because that is really what we did here, the Phase I. And at the time, it was no different than any of the other things that we were testing in Phase I, some of which did not work and some of which did, so there was nothing special about it as a category of research, in a way.

But the difference, perhaps, is that there were people who were enrolled in that early Phase I study who stayed with us for a long time and, as AZT became more accepted, either stayed on it because they tolerated it well and it was accepted, or had to get off it because they could not tolerate it well and tried something else. There were some of them who rolled over into other studies where they added things without taking the AZT away. Then there were people like the ones that we ended up on this myopathy study, who at the time may or may not have still been on AZT, but many of whom, though not all, were from that original cohort and had been on it for a long time.

What we have certainly learned about since is a lot of the community reaction to AZT and how people hate it. We did not see that so much because we were...it was early, nobody knew enough about it to hate it, and the people who came here were the ones who were willing to try it anyway, so we did not get that kind of attitude from the patients that were here.

Hannaway: It is only longer term that this has become more apparent and longer-term effects have become more apparent, obviously, too.

Harden: Do you want to make any final comments? We did not really get you to talk too much about your book, on your view, after having written this, on the future of AIDS vaccines. Are we going to get one soon?

Grady: I hope we are going to get one. I do not know that I will comment on the “soon” part. It is hard to say. I mean, right now everybody’s looking carefully at canarypox and hoping for something there. From what I have read about it, it certainly looks as though it has some potential in terms of being able to stimulate both cellular and humoral immunity, and that is, at least to the degree that we understand immunopathogenesis at all, those seem both to be necessary

in this particular case. But whether or not they are adequate and whether or not the canary pox will elicit adequate responses is still, of course, questionable.

People were very excited recently about this DNA, naked DNA vaccine, but I have heard other people say there is dangers lurking that we have not yet uncovered because we do not have enough experience with it. They are using a similar approach in other diseases.

But I think the only way we are ever going to get a handle on this epidemic is through a vaccine. I am fairly convinced of that. So I am very hopeful that there will be one, and I think that there is certainly enough scientific interest and some very good scientists who are working on it. You could argue about whether there is enough money and enough people and all that. There is always room for more, more money, more people, dedicated to that.

I think this current discussion about whether we need a March of Dimes. What was I reading in the paper this morning about [Dr. Myron] Max Essex saying we need a March of Dimes effort or a Manhattan-Project-type approach. It is an ongoing battle. Some people say that will work and some people say it will not work unless you have the science. It will not work unless you have the science, so I do not really know whether that is the right approach. I certainly think more money could go into vaccine research without being wasted.

Hannaway: Some have the perspective that if a treatment that at least keeps HIV under control becomes the predominant way of trying to help those with the disease in America, that the interest in vaccines for the developing world will decline. Would you have an opinion on that?

Grady: I am afraid that is probably true. The sad reality of the economics of it is that developing anything, including a vaccine, is very expensive and market-driven to a large extent. Even though the need in the developing world is enormous and will continue to grow, the ability to support economically either the product or the process does not exist, and that is a problem.

Harden: We have just about exhausted our questions. I always like to ask if is there anything else that occurs to you that, points that you would like to make, before we stop?

Grady: Only one, and I may have said it already. But I think the experiences that I have had as a nurse in HIV have confirmed, probably, an opinion that I have held for a long time, and that is that nursing is a wonderful profession. The nurses that I have had the opportunity to work with in this context are sensational, almost without exception, courageous, committed, hard-working, very good people.

Harden: This is sort of a special situation in one sense at the Clinical Center, perhaps.

Grady: Right. But also all over. I have had the opportunity to be involved in a continually growing network of nurses nationally that created an organization some years ago, the Association of Nurses in AIDS Care. In the early days, there was a handful of people from all over and we all knew each other. And we still see each other sometimes. Some are no longer involved in that group, but most still are. Although the number of people involved have grown—I do not know them all, obviously—but that initial group was a very special group of people.

Harden: Thank you very much. We appreciate your talking with us.

###