

This is an oral history interview with Barbara Baird on 17 March 1993 at the NIH Clinical Center, Bethesda, Maryland. The interviewers are Dr. Victoria A. Harden, Director, NIH Historical Office, and Mr. Dennis Rodrigues, Program Analyst, NIH Historical Office.

Rodrigues: Would you begin by telling us about your background and training and what led you into a career in nursing?

Baird: As a young adult, I was originally trained in pharmacy. I had gone to George Washington Pharmacy School in Washington, D.C. This was before it was closed down. Before graduating, I got married and moved to California with my Naval officer husband. I was a homemaker and had three sons. About 15 years later, we moved back to the Washington area. By that time the pharmacy school had been closed, so I could not continue my pharmacy degree. I had always been interested in the health sciences, and George Mason University was opening a new nursing school. Many of my credits could be transferred and I was accepted as a member of the second or third class of nursing students.

Harden: Had you grown up in the Washington area?

Baird: I actually grew up in the Pittsburgh area. My young adult life was in the Washington, D.C., area going to school. I lived about eight years in California and then we returned to this area. I decided to go back to nursing school as my children were already in school, and I was getting a divorce. I graduated at George Mason in 1979. After receiving my degree, I worked for a couple of years in Northern Virginia, which is where my home was at the time. I met a person who had been a patient at the National Institutes of Health [NIH]. He told me how great the NIH was and how impressed he was with the care and the research there. I began to look for a position in the Nursing Department at NIH. I found a position as a staff nurse on Eleven East in the NIH Clinical Center.

Harden: What year was that?

Baird: It was 1981. The eleventh floor of the Clinical Center was where patients with immune disorders and some with infectious diseases were housed. These were all National Institute of Allergy and Infectious Diseases [NIAID] patients. I actually worked for the Nursing Department, which was under the Clinical Center.

Harden: What month did you come?

Baird: March 1981.

Harden: That was definitely before the first publication about what came to be called AIDS.

Baird: Absolutely. We had some patients who had genetic immune disorders, some had infectious diseases, others had acquired immune disorders from other causes. We did not have any cases that resembled HIV infection until about December of 1981. Dr. [Anthony S.] Fauci would conduct rounds. That was when his office was still over here in Building 10. I was attending rounds one morning, and we had a patient on the floor who had an unexplained immune dysfunction. During rounds, outside this patient's room, Dr. Fauci expressed concern and was wondering if this patient's case was similar to some he had read about in the *MMWR (Morbidity and Mortality Weekly Reports)*, which is the Center for Disease Control's [CDC's] publication. The article was about a number of gay men who were showing up with a type of immune disorder. Dr. Fauci said that he did not know if this man had the same disorder. There was also some speculation in the group of physicians and nurses as to the man's sexual preference, because at that time we did not query patients about lifestyles. That would have been considered irrelevant information. That was the first time, I think, that anybody had any awareness that something new was going on.

Harden: That was December of 1981?

Baird: Yes, about November, December 1981, or January 1982. We continued to watch that patient. We also did not know that there was an infectious agent causing the disorder. At the time, there were three major speculations about the cause. I remember attending one of Dr. Fauci's lectures in which he discussed how researchers could not determine the cause of this immune dysfunction. At the time they only saw the disease in gay men. They thought that maybe the body was having an immune reaction against the sperm, so that when another male was exposed to sperm, his body would develop an immune response. They did not know whether it was that, or perhaps a response to nitrite usage, because many gays would use "poppers," which contained nitrites, and we knew that certain chemical exposures could cause immune disorders. An additional speculation was that it was caused by some infectious agent that we did not know anything about and had never seen.

Harden: Were you personally attending this first NIAID AIDS patient? How many nurses probably would have been involved in his care?

Baird: Probably about six, because we had three shifts. The patient had a primary nurse, but during the other shifts, other nurses attended him. We covered Eleven East and West. Sometimes the nurses would cross over and double cover each side. The patient probably had about five or six different nurses. I did not attend him very closely. He was one of the first patients, and I only knew him in a peripheral way.

Harden: Was the nursing staff given any kind of guidelines at the outset in terms of special

safety precautions to take?

Baird: No, not specifically. However, we all knew the standard infection control guidelines that were in place at the time and we implemented them when appropriate. The HIV guidelines began when I had my first primary patient. It was at that time that Dr. David Henderson, who is the Clinical Center's epidemiologist, came to me and said that he and other physicians thought that the male patient whom I was attending might have an infectious disease and that they needed to see how I was taking care of him so that they could develop some specific infectious disease guidelines. He asked me what kind of precautions I was instituting. I said that the patient had diarrhea, and I described how we dealt with that. We went through the list of the patient's symptoms, and I told Dr. Henderson what precautions I was taking. I did not wear a mask, but I wore a gown and I wore gloves.

Harden: I remember reading about Dr. Henderson's guidelines, and I would be very interested to know just how they were developed.

Baird: I did not realize the implications at the time nor did anyone else. I was just using standard precautions when Dr. Henderson asked me to tell him what specifically I was doing because he wanted to write guidelines for this particular situation. A couple of years later, I thought about the pretty remarkable things that had happened then, even though we did not know what was going on.

The particular patient that I was caring for was from New York, and he happened to have cryptococcal meningitis. I knew that the disease he had was possibly infectious and it was affecting his brain, causing him to have some odd behaviors. For example, he would walk out into the hall without his pajama bottoms. He also had difficulty with personal hygiene. He was also incontinent of stool, he could not always get to the bathroom in time. He would have diarrhea on the floor. He also had difficulty with coordination and would sometimes spill his urinal. With those kinds of risks, I wore gloves, a mask, a gown, and even sometimes shoe covers because, if I went in the bathroom, excretions might be on the floor. If I was going to do anything where I might aerosolize the urine, then I wore a mask so nothing splashed on my face. If I changed the bedding I would wear a gown. However, if I was just taking in his food tray, I did not wear any special covering. It was also important not to make the patient feel any more isolated or alienated than he did already. Handwashing was one of the most essential and critical elements of infection control.

All of the precautions I was using were adopted as the protocol for these patients with AIDS. I did not know that I was protecting myself against HIV because we did not know then that AIDS was caused by a virus. At that time some nurses were wearing gloves when they drew blood and some were not. I think I wore

gloves most of the time, especially if I was going to have my hands in anything, because my hands were chapped and I knew I would be at risk of absorbing something. I probably wore gloves a lot.

Harden: Were gloves specified in those first guidelines?

Baird: Yes. I think gloves have been recommended from the beginning.

Harden: Was everybody good about abiding by these guidelines?

Baird: At first they were not because any kind of change is difficult to implement. It was usually forgetting rather than lack of desire to comply. Many times nurses would go into a patient's room, and simply forget to take the precautions and it seemed like too much trouble to go back out into the hall to get the gown, gloves, and so on. The importance of the precautions had not really been instilled in the nurses. As soon as staff education was in place, people started following the guidelines, but it was fascinating then to see how everybody went too far in the other direction. Everybody then dressed from head to toe, with shoe covers, mask, gown, gloves, and goggles just to go into the person's room. It was a response of fear among many of the personnel.

Harden: Did this response occur before HIV was identified as the cause of AIDS?

Baird: Yes. The housekeeping, nutrition, maintenance, and phlebotomy people were all fearful. Some of the nurses, some of the nursing assistants, and some of the clerks were also fearful. While it was difficult to get some nurses to wear the appropriate garb, other people wore too much, which was also inappropriate.

If I wanted to send a patient down to the Eye Clinic, for example--and this happened several times until we finally got it sorted out--the Eye Clinic would require that the patient wear a gown, a mask, and gloves. I told the Eye Clinic personnel that they were not at risk. The patient did not need to be walking in the hall with all this garb on, and if they wore gloves and washed their hands that would be adequate protection. The patient would only need a mask if he was coughing. They did not believe me, and this sort of reaction continued for a while.

If the cleaning people went into a patient's room, they went in gowned from top to bottom or they did not go in. A room would not be cleaned for a week or so before we realized what was going on. The nutrition people would leave the trays outside the patient's door, they would not take them into the room. After much staff education, after the virus was identified, after the CDC and others identified the appropriate precautions, and after many classes for nutrition staff and other personnel, people finally got it right.

Harden: It probably helped, too, that doctors and nurses were not getting AIDS. It became obvious that people would not get infected just by walking into a patient's room.

Baird: It was a case of "I will watch you and if you are all right, then I will do what you are doing. It must be okay." But the fear was overwhelming. I would sometimes get a call from the X-ray department if I sent a patient down there. The people there would say that I needed to tell them about these patients because they were ten times worse than a patient with chicken pox. I would reply that this was not so. Chickenpox is transmitted by droplets. This disease is not transmitted that way. This was after we knew it [AIDS] was caused by a virus.

The fear was a big problem and it probably still is in some rural sections of the country. Staff education and development have improved the situation [in hospitals]. People now use appropriate protection and do not take unnecessary risks. When people do not wear gloves and take appropriate precautions, it becomes a safety issue. In contrast, too many inappropriate precautions have the effect of making the patient feel unclean, isolated, and rejected. You have to strike a balance between protecting yourself and not having the patient feel like a leper.

Harden: Were you in a management position at this point in relation to the other nurses? Were you trying to educate them, or were you more or less taking the lead on your own initiative?

Baird: It was more or less the latter. My children were grown, and I was not anticipating getting pregnant. Caring for patients with viral diseases is always a problem for a nurse who is in the stage of her life when she can get pregnant, because of the effect that some viruses have on a fetus.

To be on the cutting edge of characterizing a new disease was fascinating. About a year later I went to see Dr. Henry Masur regarding a position he had for an AIDS nurse. I said to him, "I have read everything written on AIDS." Of course, that only lasted one year. I was very interested in knowing what the latest developments were and I would volunteer to take care of every AIDS patient who came on the floor. The other nurses were very happy to allow me to take care of these patients. There were two or three patients, and I would always take them as my assignment. These patients needed a lot of nursing care, because of dementia, incontinence, and the many medications they were taking. It was very good experience, interesting and depressing at the same time. Dr. [Clifford] Lane was a good teacher. He would always explain his plan of care to me and the related pathophysiology. It was a very good learning experience at the time I was a staff nurse.

Harden: How many AIDS patients were there in the Clinical Center before you began working with Dr. Masur in October 1983?

Baird: There were probably three or four AIDS patients between 1981 and 1983. There was one patient whom I cared for, actually, for a whole year. I was his primary nurse. He was an in-patient for a whole year. In fact, the *Philadelphia Inquirer* writer Donald Drake came down and did a feature article on him. He was one of a pair of identical twins. He was the very first twin with whom Dr. Lane did research. We did not know that the patient had HIV at the time, but Dr. Lane knew that the man was an identical twin, and that his immune function was depressed. He knew the man had an identical twin brother who was not gay and who had intact immune function. His goal was to reconstitute the immune system of the sick twin, without knowing about the virus that was there.

For a whole year the patient received interleukin-2, but it did not do anything for him. I think he also got gamma interferon. He was a very good patient because he was intelligent, articulate, and compliant. He was very good for the purpose of conducting research. Toward the latter part of that year, Dr. Lane decided to do a bone marrow transplant [between the twins]. Up until this time, nothing was working. When he did the bone marrow transfer, the patient had a little reaction, he got a rash, which was considered a "graft-versus-host" reaction.

In the subsequent follow-up laboratory work, Dr. Lane showed me how the patient's immune function had improved temporarily, but after a period of months, it dropped back down again. Dr. Lane said that there was something in this man's bloodstream that was causing his immune function to go down. Until we found out what that infectious agent was, we really needed to approach the problem from two perspectives. He said that an anti-viral agent was needed, which later turned out to be AZT [3'-azido-2',3'-dideoxythymidine], and he said that we needed something to boost the immune system. Conceptually, Drs. Lane and Fauci were the leaders in the field.

In August 1983 the twin died. During that year Dr. Masur had come to the NIH from New York. He had been one of the first physicians in New York to identify the syndrome in women. Dr. Lane and Dr. Masur began to collaborate. Dr. Masur was with Critical Care Medicine. Dr. Lane was with NIAID. Dr. Masur was also board certified in infectious diseases, therefore his interest in AIDS. Many of these patients who had pulmonary problems would be sent to Dr. Masur's Critical Care Medicine Unit to get a bronchoscopy. It was a natural collaboration for the two men as both had the same interests and, of course, they both were interested in what was happening in these patients and why immune dysfunctions were occurring.

Dr. Lane told me that Dr. Masur was looking for someone to replace a fellow who

had been doing some research for him. He said that Dr. Masur thought that a nurse would be a perfect person for the job because the job required someone who could identify clinical problems, such as when a patient called and said that he had a fever or some other symptoms. In addition, a nurse could also evaluate laboratory work, and a nurse was very detail oriented. Dr. Lane also said that Dr. Masur was married to a nurse, and that his understanding of a nurse's strong points, the strengths that a nurse has, was very good. Actually Dr. Lane was also married to a nurse, so both of them knew about the knowledge and skills of a nurse. Dr. Fauci also married a nurse. Dr. Masur interviewed me and asked if I would be interested in the job. Basically, the job included a wide range of tasks: seeing the patients in the clinic; giving the medications; gathering the data; and doing laboratory work. I was to draw all the bloods, take them down to the laboratory, centrifuge them, and pipette them off into small tubes for frozen storage. Nurses are not trained for laboratory work, but Dr. Masur said that he would teach me. Dr. Masur also said that he wanted me to learn how to use a computer program so that I could keep the data for this project.

I subsequently took the job and about a week into it, I thought, "What have I gotten myself into? Computer work, laboratory work, is this really what I want?" But it was fascinating, and Dr. Masur was a good teacher. He made available to me all of the resources that I needed to learn. I went over to the computer building. I was tutored over there, and I would study the books at night. Then I went down to the laboratory, and the people there showed me how to pipette the blood off. Looking back, I realize that I was not in the appropriate environment as it is now done in the laboratories. I was just wearing a gown, a mask, and gloves to pipette the blood off. Now, all this is done in an P4 [facility]. There was not even any hood because there was so much we did not know, and we thought that it must be safe. Fortunately, I only did this for two to three years. Because the program expanded, laboratory persons were hired for the blood work and they did the work under hoods.

Harden: Would you explain a little more about what the purpose of gathering this information was? What were you looking for in that blood? What data were you getting from that blood?

Baird: Dr. Masur had two interests: first, he wanted to characterize this disease; and second, he wanted to store the patients' sera so that at some point when we did develop a test, we could do the test on the frozen sera. This is, in fact, what did happen. In 1984 we tested the frozen sera with the HIV (HTLV III) test. Dr. Masur wanted to characterize the symptoms of HIV disease and he wanted to characterize the opportunistic infections. He was interested in identifying the pulmonary processes, because many of these men were showing up at the emergency room with *Pneumocystis* pneumonia unable to breathe. Dr. Masur wanted to know if we could intervene earlier. He wanted to identify some of the

earlier signs and symptoms, and he considered whether we should be suggesting some prophylaxis. He had many questions. He was a visionary; he wanted to collect the information. He may not have known what the information meant or how to apply it at the time, but he felt certain the information would come together to indicate something meaningful.

Harden: In your computer program, you would plug in that today you saw a patient with *Pneumocystis* pneumonia and X, Y, and Z symptoms, and then you would draw blood from the patient and centrifuge it. What else did you do?

Baird: At that time, also, in my computer program I had the names of all the HIV patients, their NIH numbers, and their diagnosis. For instance, if the patients had *Pneumocystis* pneumonia they would be in one group, if they had Kaposi's sarcoma they would be in another. If they had started any drugs or any studies, that date was listed; if they had been on any other medications, that was listed; and also their status. At the same time that I was generating this program and these data, the NCI [National Cancer Institute] and NIAID were collaborating. A group met every Wednesday. The group included [Dr.] Ed [Edward] Gelman, [Dr.] Dan [Daniel] Longo, Joan Jacob, and several other investigators from the NCI, [Dr. Abraham] Abe Macher from Pathology, Clifford Lane, and several others from NIAID, and Henry Masur and myself from CCMD. The investigators from NCI thought that they should give the patients with Kaposi's sarcoma, which is a neoplasm, chemotherapy, but they were not certain what the chemotherapy would do to the immune system. So the Cancer Institute was naturally approaching the problem from the direction of oncology, while Dr. Lane, who was looking at therapy with gamma interferon and IL-2 [interleukin-2], was approaching the problem from another direction. Dr. Masur was focusing on the pulmonary problems and diagnosis of *Pneumocystis* pneumonia, and on prophylaxis. The group problem solving was very stimulating intellectually as well as developing new approaches to the problems.

My job was to gather information on everything that the members of the group were doing and get it organized. There was one other nurse, Joan Jacob, who worked as a study nurse with the Cancer Institute at the time. We were the only two nurses, everyone else was a doctor. Joan was keeping track of the NCI patients, but she did not know how to use the computer. She would give me the names and information, and each week I would generate a table for each study. One study was a six-drug chemotherapy for Kaposi's sarcoma. I would create a list of who was on that study, when they started, when they stopped, and their response to the therapy. Fortunately, there were not that many studies and not that many patients, perhaps about fifty. I worked a lot of overtime trying to manage all the data, but it was manageable then compared to the large volume of data now. The program is probably 30 times larger now than it was at that time.

Harden: Is this computer program still being kept up?

Baird: Yes. As the program grew, big pieces of what I was doing were taken over by other people. For example, there is now one person whose task it is to manage the laboratory and data entry. Every week we are given a list of all the study participants and their laboratory data. A computer programmer has designed a program to put in data from several sources. We also have case managers now who see the patients in the clinics. That was another part of my function. Then we have study coordinators who run the studies for various research drugs. That was another task I did. Then there is also recruitment. We have another person who contacts the community information networks, decides [whether] to advertise or not, and sends announcements to the newspapers. She and her staff are another part of the group. What I was doing in my job has now been expanded to a large group of about 35 to 40 people. It is very nice to see the program grow to that extent.

As the program was expanded, it was also refined. Dr. Lane and Dr. Masur remain the two physicians in charge, but now they have another level of positions below them. These are the PI's [principal investigators] of which there are eight. The top two in the organization are Dr. Lane and Dr. Masur, and then, at the next level, are the attending physicians and the principal investigators. They write all of the protocols in cooperation with Dr. Lane and Dr. Masur. Half of the study coordinators work for NIAID and the other half work for the Clinical Center under Critical Care Medicine. The case managers work for the Nursing Department under the Clinical Center. In addition, there are laboratory and data management people. It is a quite a large organization.

Harden: In their roles as case managers, have nurses moved into job classifications other than nursing?

Baird: No. The primary classification of the nurses is nursing. At first I had many additional functions than just nursing. My job title was a "health specialist." This was a new role for a nurse. Therefore the job description was new and for several years it was only temporary. Then my position was later written to include more nursing functions, and I became a "nursing specialist." Each time I was to be promoted, the job description had to be rewritten. When I became a twelve [GS-12] was the last time it was rewritten. I doubt if it can be rewritten as a GS-13. All the study coordinators are at a GS-12 level. Since I am the study coordinator who has been here the longest, I have a window in my office. The other study coordinators said that not only was I the oldest but I had been here the longest, so they thought that I should have the window office. There is some deference for age and experience.

Rodrigues: This implies that you acquired this particular office later. Initially was your office

on the eleventh floor [of the Clinical Center] or somewhere else?

Baird: Initially, I had a cart, and I pushed it around from floor to floor. I had no office, no desk, nothing. I had no base because there were no offices. Space was, and continues to be, a problem. Dr. Masur told me that I could put my personal things in an office of one of the anesthesiologists in the department who was away for six months. I had patient files, test tubes, syringes, and other items on the cart. When I was given some space, I kept the cart around just for sentimental reasons. When I was using the cart, I would cover it over at the end of the day so no one could see what was on it, and I would try to find a corner somewhere to put it. I did not want people taking syringes and so on. The cart would not fit in anyone's office.

For a couple of years I worked from my cart, and then I started sharing offices. Critical Care Medicine is like a step child. It is not an institute, so its space is very limited. For a long time, about a year or so, I shared an office with someone on the fifth floor in the clinic, but this was Neurology's clinic, so we knew it was just temporary. Then we were moved to another office about eight feet by ten feet in size, with three people in it. It was essentially a hallway, because people had to walk through to get to their office. That was one of the worst situations. Then the eleventh floor was organized to have clinical space, so we moved to the eleventh floor. This clinic on the eighth floor [we are in now] was just opened about three years ago. Actually, Dr. Lane, Vicky Davey, and Bill Barrick designed what they wanted for the clinic. The case managers have the largest rooms, since they see more patients and occasionally do a physical assessment. The study coordinators have the smaller rooms since we see fewer patients than the case managers. Our primary role is to manage the whole study so we will do the initial assessment of the patients. There are two doctors in the clinic. We have been based here for about three years, and these have been the nicest surroundings that we have had. We all have computers, and we have all sorts of support staff to help us, too.

Harden: As a study coordinator, do you do only one study, and another study coordinator manages a different study?

Baird: Usually. Sometimes we will manage two or three studies at the same time. Right now I am managing two studies. One of them is moving quickly and one of them is moving rather slowly.

Harden: What are they on?

Mrs Baird: One of them is evaluating a drug for toxoplasmosis. The drug is 566 C80, or Mepron, and it was approved by the FDA [Food and Drug Administration] last September [1992]. It had already gained approval for treatment of *Pneumocystis* pneumonia, although it treats both infections. It is an anti-protozoal agent, so it is

effective both against *Pneumocystis* pneumonia and toxoplasmosis. It was approved for treatment of *Pneumocystis* pneumonia, but we know that physicians in the community are probably writing prescriptions for it for toxoplasmosis. The Burroughs Wellcome Company, which is the drug company that makes it, decided to close those studies and gather any other data in another fashion.

I am continuing to manage that study. There is just one person on it and he is still doing well. He comes in every three months, and when he comes in, he sees the case manager. For the months he does not come in, she calls his doctor and gets the information faxed to us. We keep track of the patient on a monthly basis, even though he only comes here [to the NIH] once every three months.

The other study is on a new drug called HPMPC. This is made by Gilead Pharmaceuticals, which is a new, very small drug company in San Francisco. This drug has activity against CMV [cytomegalovirus]. We started this study in September [1992]. We are now fifteen patients into the study. Tomorrow I will screen the sixteenth patient. The study is for sixteen patients. The drug has shown some good effect against the virus. It has some toxicities that we are trying to control. We have had several amendments and changes to the protocol as the study proceeded.

A few years ago, in 1985, I worked on the ganciclovir study, and that drug finally was approved by the FDA for the treatment of CMV retinitis. Then, in 1989, I managed the foscarnet study. The data from the studies at the NIH was very influential in obtaining FDA approval. I have been fortunate to be involved in studies of a number of drugs that have received FDA approval. It is a nice reward, after the hard work of gathering the data and getting it organized, that ultimately, there are millions of people getting this drug that would not ordinarily have done so because we have done a good job.

Rodrigues: Would you say the NIH was unique in using this approach to research in which nurses were more involved?

Baird: Yes, we were unique. Now, I think we see a lot of copying. I think the extramural program has realized that this type of research is a good area for a nurse. A nurse works well in such a position because she can deal with diverse tasks. The extramural program now has adopted this, and even some private, non-NIH funded groups are using nurses [for such research]. Ten years ago, they were using medical students or doctors just out of medical school. Research was not the domain of a nurse. The nurse now has very nicely fitted in, done a good job, and gained acceptance in doing this kind of work.

Harden: Do you think that the acceptance of nurses in research occurred now because society decided that women might have heads on their shoulders and be able to do

things like this, in contrast to a couple of years ago when it was just assumed that they could not?

Baird: I think it all went together--there were many more female physicians, and nurses were given more responsibility. I know the NIH is a unique place because I formerly worked at Northern Virginia Doctors Hospital. This was a doctor-controlled hospital. The atmosphere was incredibly different. Of course, this was ten or twelve years ago. Then, when a doctor walked into the nurses' station, the nurse stood up. The nurse gave the doctor her seat and she stood. When the doctor wanted to make rounds, the nurse walked behind the doctor with the patient's chart. They had a protocol for the way the nurses should behave that was clearly out of the nineteenth century. I am still certain a hospital functions this way in many parts of the country.

At the NIH and at some of the larger hospitals we have seen an incredible transition in the past ten or fifteen years. For instance, nurses are now no longer wearing their caps. Most nurses liked wearing the caps and uniforms because it was distinctive. It separated them from the laboratory technicians, and the floor washers. But what happened was that nurses felt they were being identified in a demeaning way. They thought that the cap was demeaning because it had its origin as a dust cap. Then, they also felt that the uniform was demeaning. Many nurses have gotten away from wearing the uniform. All of these changes have occurred. The uniform is not being worn in many places, the four-year nursing degree program is now being required by many hospitals. There were two kinds of nurses' training, but diploma schools are now out of existence. In the nursing field itself there have been many changes--the acceptance of nurses by doctors, and then women's rights and so forth. This is a great time for all this to occur. It has been a change for the better, there is a health care team now.

Harden: Would you say, then, that professional protocol means very little at the NIH, that the nurse does not have to waste energy worrying about whether she is standing behind a doctor or in front, that there is more of a partnership?

Baird: Yes. The other beautiful thing at the NIH is that there is no profit motivation. When you work here you do not realize that this can be a problem elsewhere. If you work in a community hospital, or even in a medical center hospital that is doing research, there is still some profit element. This requires the doctor and everyone else to think twice about whether or not they want to do a test or how much it costs. The minute you have to think about how much something costs, it is going to affect the pureness, so to speak, of your job. You cannot think only about the research, you have to think about the money. You cannot think about what is the ideal approach because there are always budgets and monetary things to worry about. Here, there is not this constant profit issue. Without that pressure, doctors and nurses work more as colleagues, as a team rather than as a

hierarchy. You do not see the hierarchy at the NIH. We all gather on Friday afternoon, and we have everybody there, from the directors, Dr. Lane and Dr. Masur, to nutritionists, pharmacists, case managers, nurses, and nursing assistants. Everybody is in that room and everybody has input as to the care of the patient whom they are discussing at that time. It is truly very team oriented, and there is no hierarchy to worry about. That is very conducive to good work.

Harden: Do you know about how many AIDS patients are in the Clinical Center now, in 1993?

Baird: Well, besides those in the Clinical Center, you also have people who come in once a month, and people who come in once a week.

Harden: How about in-patients?

Baird: That would be a very small number. I would say there would not be more than five in-patients. The in-patient population is very small. Among the out-patients, you have the pediatric cases of Dr. Phil [Philip] Pizzo. You have the NCI's adult patients, and then you have the NIAID patients. Also, the Division of Transfusion Medicine is doing some work [on AIDS]. People ask for the number of AIDS patients frequently, but it is a hard number to get hold of unless you can be more specific. If you want to know how many people have been seen here from once up to ten times, you can get that number. Epidemiology probably would have it. In the past, for the longest time, I kept a list of those numbers. When a person came in with AIDS, he or she was given an NIH number. I kept them on a list, but once it went over a thousand I could not continue it. That was another job I had, tracking all the patients and reporting them to the Centers for Disease Control. When the numbers became large, Epidemiology took over the list and hired a nurse to work on it.

Rodrigues: I went through Grateful Med and pulled out articles using some term having to do with nursing, AIDS, and research. I was surprised to find quite a few articles in nursing journals still dealing with the topics of the stigmatized patient, homophobia, and so on. Were these issues ever a big problem for the Clinical Center, in terms of finding nurses who wanted to be part of this program?

Baird: At the NIH, it actually was not. There were more nurses who volunteered than were needed. It was like the hospitals in San Francisco. There were more nurses volunteering to take care of patients than those who did not want to do it. Geographically, that has not always been the case around the country. In New York, there were nurses being forced to care for patients, and the same thing with doctors, too. There were also problems in the Midwest, the Southwest, and the South. Because of the fear, there were legal cases in which nurses were suing because their employer was forcing them to take care of AIDS patients. They

thought they were at risk, or they thought they might be pregnant, or their husbands and families objected. It is not as much of a problem now. I think it is ebbing, but it is still a problem in some places.

There are ethical issues involved: I am a health care professional, but can I choose to whom I deliver my care, or don't I have a choice? Does the Hippocratic Oath mean that I have to care for everyone? The Constitution says that we are all created equal, and, in fact, it is illegal if I do not care for minorities. Where does AIDS fit into this? Is having AIDS the same as being a minority? Now that AIDS is known to be infectious, what are the ramifications of that? It is very difficult. But it is nowhere near the problem that it used to be.

When this epidemic first appeared, I was hired by a firm that does education for nurses. They developed a one-day program and sent me around the country on my days off. I would take three or four days of annual leave. I would go to various cities, and the company would have a conference set up at the local hotel. I would talk to nurses, tell them how to deliver care to AIDS patients, and describe what to expect. Very early on, I could hear from their questions that people were afraid, that they were resentful. They did not want to have any part of caring for AIDS patients.

Harden: What were they afraid of? Were they homophobic, or were they afraid of a disease that they did not know?

Baird: They were afraid of what they did not know. It was also interesting that many times the nurses were willing to care for the patients. But their husbands were not willing for them to care for the patients. Many husbands had much to say about who their wife was going to care for, because they were both working. Many nurses said to me, "I don't mind doing this, but my husband doesn't want me to because he doesn't want me to bring this home." There were a number of those comments but there have not been so many recently. There is a little here and there, but it is nowhere near the same. It was the fear. With the husbands, it was clearly fear because they did not know what the nurses would be involved in so they could not really make an intelligent decision about it. Does that answer your question?

Rodrigues: Yes, it certainly does. I was surprised, because until I looked at some of the more recent literature, I did not realize that these views were still circulating.

Baird: My brother lives in Oklahoma, and up until now, you can talk to people there and they will say: "I wouldn't take care of any AIDS patients." There are pockets in this country where people would say that they would not take care of AIDS patients. Then, of course, the Moral Majority thinks that AIDS is the result of God's will. There are fanatical religious groups that account for many patients coming in with a lot of guilt associated with their disease. They feel that they are being punished for something they did wrong.

Rodrigues: I assume that the vast majority of the patients that you have had are gay males, although you did mention the pediatric cases, and I am sure there are hemophiliac cases as well. How would you describe the gay male AIDS patients as a patient population compared to, let us say, the cancer patients? Do they tend to be compliant with the different research protocols or, with all the political activism, is there a certain amount of hostility on their part?

Baird: It is all on a continuum. You have people at both ends, and then you have people in the middle. With AIDS, there tends to be a little more of the activist mentality, and it is unfortunate. If you compare the AIDS patients to the cancer population, you would see that they are different. However, if you interact with someone, if you can get them to put their activist behavior aside, and interact with you on a person to person level, then it is a positive interaction. Many times men will come in and I know that they are from ACT-UP or some other group. I will say to them, "I am not here for your political issues, I am here to take care of you. Let us see what we can do, what study we can get you on, how we can get this study done." Much of the time you can divest them of that anger and hostility. If you can, then you can work with them a little better, so that is one difference.

As a group, because they are not married with families, gay males have more time available. I think that is why they are able to do more activist things. Cancer

patients are usually involved with their families, and they are often taking care of their spouses and their children. Many of the gay men may have significant others, and may be part of a couple, but they most often will not have a large family unit or minor children for whom they are responsible. I say this only as a general rule, because there some gay males who do have such responsibilities.

Harden: The NIH intramural program, has, on occasion, gone above and beyond what is required. In one personal experience I called the nurse in charge of a *Cryptosporidium* study on behalf of a friend whose nephew had AIDS. She arranged to talk with the family and also for a consult for his attending physician with the doctor in charge of that study. I am not sure that it made much difference to the patient, but it certainly made a lot of difference to that family, feeling that the leading federal government center on AIDS cared about them.

Baird: Often people will call, and they do not understand the mission of the NIH. They think that we are here to do patient care like most hospitals. Other times they call from all over the country because we have a 1-800 number. What they want to hear is that they are getting good medical care. They want to be reinforced in that way. When I say, "What is your disease? What treatment are you getting?" and they tell me what they are getting, I can tell them whether it is standard medical practice. I do not tell them whether their doctor is good or not because I do not know. If I tell them that they are getting standard medical care, that it is appropriate, and everything is fine, then they are satisfied.

Harden: Obviously, to watch a young person suffer terribly and die is terrifying for a family. Just to have somebody assure them that they are doing everything that they can is comforting.

Baird: Yes, the big fear is, "Am I doing everything I can?" They will call around to see if there is anything that they do not know about. I assure them that there is not. The other thing is the guilt that the parents carry because many times they do not find out about their son's homosexuality until late in the course of the disease. Many parents feel that they have done something to cause their child to become gay, or they fear that if only they had not done something else, their child would not be gay and thus would not be dying of AIDS. The parent is carrying this burden on his or her shoulders, feeling that they are killing their child. According to their logic, they caused it all. If the child is an adult, if there is some dementia involved and the patient cannot think or talk, then, that is even worse for the parents because they have to watch the mental deterioration of their child. Having your child predecease you must be one of the worst things that a person can go through.

Harden: Are there any other topics that you want to cover that we have not?

Baird: I am sure I will think of a thousand things as I drive home. There is one topic

now. I have encountered some suspicion about why I was interested in AIDS. Some people assumed that there must have been a reason why I was doing this. Was my ex-husband gay? Was this the reason that I was divorced, a mother of three sons, and I was interested in AIDS? Many people thought that one of my sons must be gay, but all three boys are straight. The answer, of course, was that the AIDS work offered an opportunity at a particular time. I just fell into it. I was right there, and I wanted to take advantage of the opportunity to learn about a new disease. For the first two or three years of my AIDS work, however, while my sons were in high school--at least for the two younger ones--it was a very sensitive issue, especially if I brought home papers from work that said AIDS on them.

Harden: Was there any fallout for your sons because their mother was working on AIDS?

Baird: No, not necessarily, because they did not tell their friends. Of course, if I had left literature lying around, there could have been a problem. Their friends were pretty close-minded, and if they had told them, I think it would have had been broadcast around the whole school. But I was essentially told by my sons to keep my mouth shut and keep a low profile. They knew that their friends would not understand.

About six years ago, when I moved into my house, a neighbor came up and talked to me. She said, "Welcome to the neighborhood," and that sort of thing and asked what I did. I said "I'm a nurse. I work at NIH." "Oh, what kind of work you do?" "I work with AIDS research." I thought she was going to kick me out of the neighborhood. She said, "If you do, I am surprised you even tell anybody about it." About the same time, or maybe shortly before that, my dentist and my doctor wrote on my chart "Works with AIDS patients."

Harden: Did they make sure they wore gloves and a mask before they examined you?

Baird: It was like I wore a big letter "A." My doctor and my dentist wanted to make sure that, if I was going to pick up AIDS at work and if I was foolish enough to work with these patients, then just because they were giving me care they were not going to be exposed. They were very careful.

Harden: I presume that you participate in the ongoing NIH study to monitor the health care personnel.

Baird: Yes. I have actually been stuck three times with AIDS needles. The first one was with the first patient, and that was terrifying because I did not know yet what the cause of AIDS was. I was cutting a needle and my hands slipped. The needle just drew a little bit of blood. I gathered my thoughts and saw that the patient was okay. Then I went out into the hallway and I saw the patient's doctor. With tears running from my eyes, I said, "I do not know what I have done to myself, but I

think I am scared." He was very helpful and understanding. That is the nice thing about this place: there is a lot of caring.

I went to employee health and they did not know what to do. But they did know that this patient was hepatitis positive, so they knew they had to protect me against the hepatitis. They did not know how they were going to protect me against the unknown disease the patient had. We did not know what he had. This was the very first patient. The nurse at employee health said "I will give you some immunoglobulin and say some prayers for you."

Harden: You did not get hepatitis? That is good because it is much more infectious than AIDS.

Baird: I got a subclinical case of hepatitis, so the immunoglobulin did protect me. My liver enzymes were followed, and they did elevate. As you said, we now know that hepatitis is much more infectious than AIDS, and I was used as the index case to show that hepatitis is more infectious than AIDS. This was a couple of years later. They were able to go back and say, "She accidentally got stuck with a needle. We gave her immunoglobulin. She got subclinical hepatitis but her HIV status is still negative."

Harden: You were fortunate. Because it was so early in the epidemic, I presume that they had not started drawing blood routinely at that time from health care personnel.

Baird: Right, the official study had not begun, but we did have an unofficial one. A couple of months after my needle stick, I asked Dr. Lane if he would do an "AIDS profile" on me. He did, and it was normal. After the antibody test became available, they started collecting serum, and Epidemiology launched this follow-up study. We all participated in that and had our blood drawn every six months.

During that next two years, I was stuck twice with a needle, but it was not directly from a patient. One was out of an intravenous line and one was out of a Hickman catheter. None of these needle sticks would happen today because of the safety measures that have been instituted. In my second stick, a nurse had left a needle on a bottle exposed. I picked it up and I got stuck. Fortunately, these needles did not have the blood of patients on them, so there probably was not as much risk as there was with that very first stick. A number of nurses in the clinic here have gotten stuck, and some take AZT (zidovudine) as a prophylaxis. Fortunately, no one has converted. It is not that easy to get AIDS even from a needle stick. I cannot remember how many sticks there have been around the country, but there have been a lot, and very few cases of AIDS have occurred. I think that is reassuring for the health care worker.

Harden: When they told you that it was going to be interesting if you started working at the

NIH, you may not have anticipated all of this.

Baird: No. I certainly did not, but these past twelve years have been a good learning experience. Dr. Masur has been a good mentor and teacher. He knows how to give you the latitude so that you can learn but still be available for teaching. After awhile, you are on your own, and you teach yourself. The doctors are now also very good in including the nurse on the authorship of papers. My curriculum vitae looks very good. I have gotten authorship on the foscarnet paper, the ganciclovir paper, and the 566 paper, because I did the work; I pulled the data together. Much of what I do on the computer is graphs and charts of these data that eventually get published in the journals. It is nice to get the recognition.

Harden: Thank you, Mrs. Baird, for talking with us.

Addendum: August 1994

Baird: The HPMPC study was completed and found not to be very effective in preventing the development of CMV disease. Currently I am just finishing a study of a new antibiotic called Levofloxacin that will be released for the treatment of multi-drug resistant tuberculosis. In addition I am working on a study to evaluate long-term survivors, also known as long-term nonprogressors. The goal is to see if there is something special about these persons that can be identified and ultimately used to help other HIV-infected persons.

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