Judith Swan April 11, 1990

This is an interview with Judith Swan of the National Cancer Institute (NCI), National Institutes of Health (NIH), Bethesda, Maryland, on April 11, 1990. Ms. Swan was formerly with the NIH Clinical Center. The interviewer is Dennis Rodrigues, program analyst, NIH Historical Office.

Rodrigues: Would you begin by describing your education and training, how you came to NIH, and where you first started working?

Swan: I received a B.S. in zoology at Duke University and went on for another year of training in medical technology. When I came up here my first job was in the Clinical Center.

Rodrigues: What year was that?

Swan: 1972. I worked on the Microbiology Service in the Clinical Pathology
Department of the Clinical Center. Eventually, all the parts of the Clinical
Pathology Department were moved together into one large area on the
second floor. I held several different positions there. When the first AIDS
patients started showing up, we did the microbiology cultures on these
patients. Someone in our laboratory was doing the parasitology on these
patients. We had a lot to do with these patients. We encountered a lot of
their body fluids.

Rodrigues: Who were some of the physicians working with the patients?

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- Swan: In the beginning, there was Dr. [Henry] Masur, who handled most of the patients. And Dr. Cliff [Clifford] Lane, there was a very early, interesting patient on the Critical Care Unit when I was in Microbiology. In 1982, I moved from the Microbiology Service and got a job working for Henry Masur on AIDS research in his laboratory. I was, at that time, his only laboratory technician. By that time, there were several patients being seen. This was before they named the disease or the virus, or even before they had isolated the virus. Even though we all were expecting some infectious agent to be isolated, we didn't know exactly where it would come from and what it exactly would be. So we had to take a lot of precautions with any kind of body fluid from these patients. When I first started working for Henry, he already had a good handful of patients there. At the time, I was also drawing blood from these patients, since we used large quantities of their blood in testing lymphocyte function.
- Rodrigues: Did you actually do the functional assays? What were the assays?
 Swan: I did blastogenetic studies, which measured the patients' response to different mitogens. I would take a quantity of blood and spin it down to isolate their lymphocytes for our assays. There was a lot infected blood around, but I never expressed my worries very much. It just was always in the back of my mind. Even though I was being very careful, it would take only one accident to be exposed to the virus. In our lab for a while, I was probably the only one working with the infected blood. Later on, as the

lab grew over the years, there were more and more people working with it. I think everyone was very careful.

Rodrigues: Obviously, you were very careful about handling this blood, but were there any pronouncements or guidelines from officials about dealing with these patients? Or were you more or less left to your own devices to institute special precautions of handling these samples?

Swan: There always have been some guidelines for handling potentially infectious biological materials. Those came from CDC [Centers for Disease Control]. If you remember, in the 1970s, they instituted different levels--P2, P3, even P4 levels. We followed P3 precautions for infectious particles, even though we already knew that AIDS was not an airborne infectious agent like *Mycobacterium tuberculosis*. We used blood and body fluid precautions. Those were already established because of other dangers, like hepatitis. When we worked in a clinical lab, those precautions were emphasized very heavily by the senior staff. It was no longer the good old days when blood cultures came down with blood all over the outside of them, and we just washed them off and put them in the incubator. If that happened today, we wouldn't touch them; we would throw them out. Anything with blood on the outside would be discarded. We also used hoods and gloves to protect ourselves. These precautions were continued into the research area, because there we weren't just getting the occasional culture infected with HIV [human

immunodeficiency virus], we were getting large quantities of that material. Once we started working on *Pneumocystis carinii* pneumonia (PCP), there were times when we'd go to the autopsy room and get entire lungs out of patients who had died and were being autopsied, and we would bring the lungs back to the laboratory. Whoever cut them up and stored them away had to follow those kinds of precautions, too. I spent six years in that laboratory, and I don't know of any serious accidents that occurred. I never heard of anyone's getting even a small exposure to any of the materials we were working with.

- Rodrigues: Did you have discussions with other people who were involved with AIDS patients and who dealt with infected material? Was there a sense of paranoia, or did people put their faith in the procedures and guidelines that they had been taught to follow?
- Swan: I think they were worried. One of the nurses who was drawing blood from patients managed to stick herself with contaminated needles three times. People, I think, were worried, because the minimum dosage of HIV required to cause infection had not been defined. We participated in a program run by Dr. [David] Henderson, who monitored our blood samples. We gave blood in a voluntary program to test for HIV antibodies. If we didn't want to know, we didn't have to give blood.
 Rodrigues: That was after the HIV antibody test was developed. How did you deal

- Swan:Before we could be tested, we didn't know, of course, but historical serumsamples were kept frozen by most of the people in our department.
- Rodrigues: Would you comment about the AIDS patients as a group compared to other groups of patients with whom you dealt? Were they cooperative? How would you characterize them?
- Swan: I haven't dealt with large numbers of patients, so I'm probably not the one to ask. As far as I was concerned, they were all cooperative. That's all I'm going to say about that. As a group, they knew more about their disease than other patients whom I've seen in private hospitals. They were intensely curious about what kinds of tests were being done and things like that. They were a very aware group of people and seemed to have more background information than other kinds of patients with whom I've talked in the past.
- Rodrigues: Were you aware of the controversy that was growing in different quarters, particularly in the gay community, about how much the federal government was doing? Did that, in any way, affect the people in the Clinical Center who were working on these problems?
- Swan: I was more involved with the patients as individuals than as members of activist organizations. I know that there was a candlelight march, but the patients themselves weren't belligerent or hostile. They were looking for something to help them out.

Rodrigues: I asked that question because we also asked Cliff Lane about this. He

pointed out that there was a big difference between what official organizations said and how individual doctors and patients behaved. Swan: I know that most of the patients felt like they had a good personal relationship with the physicians who were treating them in the Clinical Center. I know that the physicians, like Henry, would always take whatever time was necessary to talk to their patients and to explain their options. The Clinical Center personnel decided logistically how to handle patients who were being treated in the Clinical Center if they were living somewhere else. The patients also saw first-hand the fact that physicians were trying everything they could. They knew that AIDS was a disease entity that the physicians couldn't really master. They were trying everything they could, and I think the patients appreciated that.

Rodrigues: You mentioned that some of your work was assessing lymphocyte function and then later, as the work changed, looking at *Pneumocystis*. Could you elaborate on the focus of that research and your role in it?
Swan: Henry and several other people who were working with him--[Dr.] Bruce Chabner, [Dr.] Carmen Allegra, and Joe [Dr. Joseph] Kovacs--were looking for an alternative to standard treatment regimen for pneumocystis, because patients were still dying. A drug similar to methotrexate, trimetrexate, was being tested by the National Cancer Institute. Because of its attributes as a dihydrofolate reductase inhibitor, they wanted to try it

in AIDS patients for the treatment of *Pneumocystis carinii* pneumonia.

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We did some animal research, in which the animals were given steroids over a period of weeks and developed lung infection with pneumocystis. They could be treated with different drug regimens to compare efficacy. We also did tissue culture of macrophages infected with toxoplasma. Now there's a treatment with trimetrexate that is being evaluated in several ongoing clinical trials.

Rodrigues: When did you start working on that?

Swan: About 1983, I guess. At that time, we thought pneumocystis was a protozoan organism, but now it looks like it's genetically closer to being a fungus. Now they plan to try more anti-fungal agents on it. Trimetrexate proved to be effective in the rat model, and they've used it on some patients. At first they used it on the desperately ill patients who had already failed other regimens. Because of this, they often didn't get a good result, but they were learning more as time went on. One thing that was interesting to me about PCP was that when we tested people working in the laboratory, all but one had antibodies to pneumocystis. It is probably ubiquitous in the environment, but it only really takes over in patients who are very immunosuppressed and have lost some of their T-cell functions. Even though people have known about pneumocystis for years, they haven't known what it is, or what it does. We are in the process of describing this new entity.

Rodrigues: Could you could describe how things expanded while you were working

for Henry? Initially, you were his sole technician. How did large did his group get and over what period of time did it expand--that is, what was the rate of increase?

Swan: That's difficult to answer, because I left in 1987, and I think it was just a year before I left that he hired a second person in his lab. There was, however, a collaborating NCI lab. I'm not sure of the exact numbers, but there were also visiting scientists, a couple of technicians and others doing cardiac studies.

Rodrigues: Was most of your work on AIDS?

- Swan: All of my work was on AIDS. I was the only one working for Henry, so I was the only one doing AIDS. The other physicians were doing cardiac work, pulmonary work, or something else. But, eventually, with the burgeoning of the pneumocystis work, there was a lot to do, so I recruited a technologist from the clinical pathology laboratory to do the animal work.
- Rodrigues: So you had some flexibility in being able to get some help for overflow work?
- Swan: We even made an arrangement with the veterinary building to have some rat colonies over there. I also understand that they have some at Frederick [Cancer Research and Development Center]. I don't know how it works any more, but it's expanded. The two men I recruited are now working overtime. They have a lot of experience in working with the animals.

Rodrigues: In 1987 did you leave to get out of the laboratory environment?

- Swan: Yes. I'd seen my last pneumocystis lung, rat or human. Before I left, it hadn't been proven that AZT [3'-Azido-2', 3'-dideoxythyamidine] would do anything to help people infected with AIDS. There wasn't any way to be protected if you had an accident. *Toxoplasmosis* wasn't the safest thing to work with, either. It's the sort of thing that you wouldn't want to get.
- Rodrigues: How did you view your career as a technical support person working in the Clinical Center? Did you view it as a long-term career or as something that you wanted to do for a number of years and then leave?
- Swan: When I first started, I saw it as long-term career. After a few years, I changed my mind when I saw how many hazards techs were exposed to and what kind of salaries they make. My experience provided a whole philosophy about hospital jobs. I think things will change in the future. I think that in a certain sense the nursing shortage is good; the tech shortage is good. It will be good for changes that might come along for women. Nurses and techs don't get any credit for saving lives and they don't get paid well enough for their high degree of expertise. Lab work and nursing are becoming more and more high tech all the time, and the work is dangerous because of exposure to infectious agents such as hepatitis and HIV. Why should anyone do that when he or she can spend less time in school, get some kind of business degree or computer programming degree, and make twice as much money?

Rodrigues: What you're seem to be saying is that to fill those niches, administrators have relied on the moral commitment of people to dedicate their careers and lives to providing services for which they may not be rewarded financially.

Swan: Somebody is hoping that they will.

- Rodrigues: In 1987 you left the laboratory and went to the Program Planning Branch to work specifically on AIDS policy. Have you found that to be more or less rewarding than what you were doing in the lab?
- Swan: It's more interesting and more personally challenging for me. Laboratory work is a very detail-oriented--not that you don't have details in this job.
 I'm not, however, naturally oriented to the level of detail required in laboratory work.

Rodrigues: Perhaps you prefer more variety?

Swan: Variety and dealing with concepts more than details. But I really enjoyed working with the people over in the Clinical Center. I thought they were all great to work with.

Rodrigues: Thank you, Ms. Swan.

End of interview