This is an oral history interview with Dr. Abe Macher of the Public Health Service, on the NIH response to AIDS. The date is 29 April 1993 and the interview is being conducted at the Parklawn Building in Rockville, Maryland. The interviewers are Dr. Victoria A. Harden, Director, NIH Historical Office, and Dennis Rodrigues, program analyst, NIH Historical Office.

Harden: We would like to begin this interview by having you tell us a little about

your background, where you grew up, your undergraduate education and medical training and how you became interested in the problem of AIDS.

Macher: I was born in a refugee camp in Stuttgart, Germany, following World War

II. My family was lucky enough to have a family sponsor them to come to the United States and guarantee that they had a job waiting for them. I was educated in New York. I went to Queens College, which is part of the City University of New York. In the summertime, I worked in the Department of State in Washington, D.C., in the laboratory of the Foreign Service Medical Division as a laboratory technician. That is when I became interested in medicine, especially in infectious diseases, because at the Department of State Foreign Service Medical Division every parasite coming back from overseas in Peace Corps volunteers, Foreign

Service people, and ambassadors is seen.

Harden: How did you get that job?

Macher: I came to Washington, D.C., because I originally thought I wanted to be a

lawyer and work in politics. I actually served as an intern for one of the congressmen. It was a congressman from Pennsylvania, Congressman Moorehead, I believe, and I worked on Capitol Hill for half of a summer. While working on Capitol Hill, I heard about an opportunity at the State Department. They were looking for college students from other parts of the country to work in the Foreign Service Medical Division. I thought this was also interesting. I applied and I was one of three students that was accepted. So the following summer I came back to work in the Foreign Service Medical Division. Again, I was interested in politics and government, not so much because of the medical side of it, but because it was the State Department. But I became fascinated by medicine because the people in the State Department would pull me into their offices and show me all these lesions under the microscope. There were all these worms and parasites moving around. The remarkable aspect of it was that they were able to treat most of these disorders. I was very impressed because the patients would come back and they would feel better.

It was at that point that I decided to switch from law or politics into medicine and I was accepted at Georgetown Medical School. I came to

Washington and went to Georgetown. When I was a 3<sup>rd</sup> year medical student. I rotated onto the Pediatric Service at the National Naval Medical Center which is across the street from the National Institutes of Health. I had a six-year-old boy with leukemia who had a high fever, pulmonary infiltrate, and pneumonia. We were treating him with antibiotics but he was not responding and the pneumonia was getting worse. So we asked for a consultation. It happened that the consultant that month was one of NIH's infectious disease consultants who had come over across Rockville Pike to see Navy patients. His name was Dr. John Bennett. I had never heard of him or seen him before. He examined the patient with me, asked me to get a sputum container and have the patient bring up some sputum, because the boy had a productive cough. We had done that earlier, but I got another sputum specimen. Dr. Bennett and I walked over to the microbiology laboratory at Navy and he asked the technician to do a Gram stain, which is a basic stain. The technician did it. He put the stained specimen under the microscope—it was a two-headed microscope—put it in focus, and pointed to some dots-and I mean, dots.

In fact, what we were looking at under the microscope was Gram-positive dotted material. It looked like debris. It did not look like an organism. Organisms are either round or bacillary and I was looking at dots under the microscope.

Dr. Bennett said to the technician, "Let's do a second stain." He told the technician to do what is called a modified acid-fast stain. We put this second specimen under the microscope and all of a sudden these dots were glowing pink. I had never seen anything like this before. The reason my six-year-old boy with leukemia was not getting any better on conventional antibiotics was because he had a very unconventional organism called *Nocardia*.

Harden: *Nocardia*?

Macher: Asteroides, which was not responsive to the antibiotics we had the patient on. When we put the patient on the right medication, literally within days he was afebrile, and the pneumonia, three weeks later, had cleared. I was so impressed, because I had never seen anybody who had been able to do this before, that I asked Dr. Bennett–he had come by every day to see the patient–if I could come over to his laboratory at NIH to see what he did. I

told him how impressed I was.

I went over to NIH and found out that Dr. Bennett was the head of Mycology and Fungal Infections at the National Institute of Allergy and Infectious Diseases [NIAID]. Unknown to me at the time, there was a

three-year program at the NIH in which Commissioned Officers would take care of infectious disease patients. I applied as a medical student to come on rotation—it would be like an elective for me—at the NIH to see what kind of patients they saw. I said, "If they are anything like the patients I had at the Navy that would be fascinating." Sure enough, at the NIH they had an entire ward of patients that they would bring in from all over the world with fevers of unknown origin. They would try to decide what was causing the fevers. So the people at NIH did these incredible fever workups.

I applied for the three-year Infectious Diseases Fellowship at NIH, which would follow my internship and residency—you have to apply three years in advance—and I was accepted for that. So, after graduating from Georgetown, I did my medical internship and residency and then came to the NIH as a Commissioned Officer to work in the National Institute of Allergy and Infectious Diseases on their fever patients. Of course these patients had strange fungal infections, strange viral infections, familial Mediterranean fever, midline granuloma, Wegener's granulomatosis, very strange things.

But then, in the late 1970s, we started to hear about an even stranger phenomenon of young people who were coming down with *Pneumocystis* pneumonia and cryptococcal meningitis. At that time I was taking calls for Dr. Bennett from physicians who would call into the NIH to get consultations on difficult cases. That was our expertise, difficult febrile cases. Since Dr. Bennett was letting me take all these phone calls, I was on the phones at the very time when the first calls came in to the NIH about this new syndrome. I had a diary that I would keep of cases, of 23- year olds, 27-year olds, 19-year olds, 35-year olds, with *Pneumocystis* pneumonia and cryptococcal meningitis. By 1980-1981, I had lots of these cases on file. As you know, in the middle of 1981 the CDC [Centers for Disease Control] announced that there was a new syndrome as the cases from Los Angeles and New York were published. We actually brought in the first case into NIH from New York in April of 1981.

Harden: Tell me about that case.

Macher: The first case at NIH came in from New York in April of 1981.

Harden: This was the one that came into [Dr. Thomas] Tom Waldmann's

immunology service?

Macher: Correct. On the immunology service. He was a young man who had been

to Haiti. In the New York gay newspapers, it had been advertised that a

person could go to Haiti, pick up young men for ten dollars, and have sex with them for weekends or weeks, or whatever, so he told us. We found out that two of his consorts in Haiti had died of some terrible infection. He, himself, had *Pneumocystis* pneumonia, *Cytomegalovirus* pneumonia, and Mycobacterium avium. In fact, to this day, he is the classic case. He is the best teaching case there is.

Harden: Your curriculum vitae indicates that you moved from internal medicine

more into pathology. Is that correct?

I did that because Dr. Bennett was always getting biopsy slides of very difficult cases. I was the person who would take the slides, go to Pathology, get under the double-headed microscope and analyze these cases. I enjoyed looking at these cases so much from a histopathological perspective that I thought that I should get some training in pathology. For one year, 1978 to 1979, I went to the Armed Forces Institute of Pathology to do what is called a fellowship in Infectious Diseases Pathology. I enjoyed that so much that I actually went back to the NIH and did the two-year Clinical Pathology Residency, the two-year Microbiology Fellowship, and a two-year Surgical Pathology Residency.

And that is where you were when this first patient came in? I would like to pursue this.

In 1981, I was just finishing the second year of my Clinical Pathology Residency.

I would like to ask you about a couple of your papers related to the first patient at NIH–and maybe some of the other early patients. I just have a few questions.

Macher: In fact, the first case is in some of those early papers.

> That is one of the things I wanted to know. You have a paper written with people from the National Eye Institute on Cytomegalovirus retinitis, and then, one with Dr. Henry Masur, Dr. Anthony Fauci, I think, and Dr. Clifford Lane. But I am looking at the autopsy pathology paper done with [Dr.] Cheryl Reichert.

Yes, the first patient was in that paper too. One of ten of our first patients.

Nobody has talked to us much about what you were seeing at autopsy on these patients that helped to define AIDS as a syndrome. Can you talk about that for a little?

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Again, in the beginning, especially with this first patient that came to Tom Waldmann's service, until that patient came to NIH, we had just heard about these cases over the phone. They were in California mostly, in New York, and New Jersey, but we had actually never seen any of these patients. We were just telling them what doses of amphotericin, what doses of Bactrim—trimethoprim sulfamethoxazole—to use. We were helping out with medications—5-fluorocytosine—et cetera.

When the first patient came in to NIH, he was very sick. We did one biopsy after another on him, but eventually he died in October, and we did the autopsy. That was the first of many autopsies that we did. We soon realized that whatever was causing this disease was predisposing these patients to multiple very serious opportunistic infections. Even though at first we heard only about *Pneumocystis*, we were finding progressive multifocal leukoencephalopathy in the brains, *nocardiosis*, all forms of mycobacteria not just *mycobacterium avium* but *mycobacterium kansasii*, and *mycobacterium tuberculosis*, which you are hearing a lot more about now. This was because we were also bringing cases in to NIH from other institutions around the country. We would fly the bodies in, because the other institutions refused to do the autopsies.

Remember, an autopsy is very expensive and, to this day, the overall autopsy rate on patients who die in our nation's hospitals is probably no more than 15 percent. So, for every hundred patients that die, only 15 are autopsied. The same thing was true for these patients. But we were so interested in defining the true pathology that we were recruiting the cases to the NIH.

Harden:

Were you worried about your personal safety?

Macher:

We were always worried. In fact, when I was medical resident in April 1975, we received a call from the Peace Corps. They were air evacuating a 26-year-old Peace Corps volunteer from Sierra Leone, an American woman, with a fever of 106, who was very sick. When she came to us she had defervesced, that means her fever had broken, and she was no longer hypotensive. Her blood pressure was normal. But we were taking care of her and examining her, trying to figure out what was happening. We could not figure it out. One day she was listening to her husband, who was apparently in Ohio or somewhere, on the phone. She turned to us and said she could not hear any more from her ear on one side.

Now you have to understand that 26-year-old women do not suddenly lose their hearing permanently. I had never seen anything like that, especially as an intern. So I called the infectious disease specialist at the State Department where I had worked as a college and medical student and he came over. His name was [Dr. Martin] Marty Wolfe, and he looked at the patient. She also had peripheral eosinophilia, many eosinophils in her blood. She has been to Sierra Leone. I said to Dr. Wolfe, "She cannot hear. I don't know what is going on." He looked at the patient, talked to her, and examined her. He came out and told me what she had without even doing a blood test. He eventually sent her blood out for confirmation of his diagnosis. Guess what she had?

Harden:

What?

Macher:

Lassa fever, one of the hemorrhagic viral diseases. It can kill the health care worker who takes care of people with this disease. Fortunately, none of us got sick. The patient had the highest titer at that time of anybody ever seen with Lassa fever and she was subsequently used as a donor of plasma to treat other people acutely who were very sick. You treat people with Lassa fever by giving them antibodies from people who survived.

We were all pretty shaken by this, but I figured that if I could survive that case, I was lucky. Sure, the new disease AIDS—and we did not know that it was AIDS at that time—scared many of us, but we are in that business. Many dangerous things happen in what we do. After the Lassa fever case, yes, I was scared, but did it prevent me from doing the work? No. But I admit that I was scared. There were residents who refused to do these autopsies and I do not blame them. There are some centers that will actually scold a resident for not doing such an autopsy, and I do not think that is right. I think it is an individual decision. It is a life threatening decision. But that is a philosophical point and that is another hour of discussion.

Harden:

How long did the NIH continue to fly in the bodies of AIDS patients to try and get a picture of the disease?

Macher:

For a very short time. Why? Because the autopsy service was a busy service in those days and here I was bringing in these cases and they had to pay for dieners to stay overtime to do my cases as well as the regular cases. Some days we had five autopsies, not just of people who had had AIDS, and we could only do so many in a day. So the period of time when we were bringing in the outside cases was very transient because it was not cost effective, but we learned a lot. I brought in one man from Ohio, I think from Akron, who was a Haitian and we had never seen a Haitian with AIDS. But we had heard about them. He turned out to be a fascinating case. He was bisexual, and we now understood, from that

experience, that that was probably another mechanism for spread of AIDS to women and their children. Very early on, we suspected that this was not just a disease among male homosexuals and intravenous drug abusers, but probably bisexuals were giving it to women.

It got even worse than that. We had one case in which a 60-year-old man had died. It was not known why. It was at another hospital. It turned out that he had *Pneumocystis* pneumonia and other infections that are characteristic of AIDS. When his wife was told that he had this new disease, she was not only scared for herself, but she admitted for the first time that he was a pedophile. He sought out young children for sex, and he had syphilis as well as AIDS. Here was a 60-year-old man, married, who was a pedophile and infecting young children, not with just syphilis but with HIV.

Again, because of the pathology perspective that we were applying and because of the access we had to medical records, we very quickly understood the epidemiology of this disease. We got complete records, not just summaries. We were sent charts, Xrays, and reports on biopsies, plus we did the autopsy. We had a lot of information that we were gleaning from all of these cases. We did not just get a body; we got all the information. It was similar to what happened with Legionnaires' disease. When the legendary outbreak in Philadelphia occurred, all the cases were studied intensively. That is what we were doing with this new syndrome. We were studying the cases intensively. We were not satisfied just to say, "Oh yes, I see *Pneumocystis* in the lung. He died of *Pneumocystis* pneumonia." We looked at every organ in the body with all of our special stains to find out what else was in that body.

Harden:

You were aware, I presume, in working with other groups like the Fauci group, of what Cliff Lane and Henry Masur were doing. Were you meeting with them?

Macher:

In fact, we had a weekly session—I believe it was on Wednesdays at eleven o'clock in the morning—which actually went on for about a year, or a year and a half. But it was excellent because at that point we had dozens of patients. In order to keep all the information straight, we had somebody from Radiology, somebody from Pathology—myself—somebody from the Virology laboratories, somebody from Henry Masur's group, somebody from the National Cancer Institute, all meeting once a week for an hour and a half at a time to go over every case in detail so we could manage the patients' care. It was very complicated care because, in those days, we were not getting in people in the early stages of HIV infection. We only got the tip of the iceberg; we got people dying. They were very sick. In

order to give them coordinated care, you had to have an entire team from Pathology, from Radiology, going over every case in detail once a week

That system broke down because apparently one of the subgroups took some of the data that we were working on together and wrote up an abstract, or a paper, and published it. The rest of the group was angry that the subgroup took some of the data. But who cares, because we were doing it this for clinical reasons, for patient care. The meetings were stopped after that because of the disagreement. But they were excellent meetings for as long as they lasted because we gave coordinated care.

Now, Henry Masur runs the program and he is the best there is. There is nobody like him for being able to take people, put them together, and get a product out of the group. In fact, for the recent task force on *Mycobacterium avium*, Henry Masur brought in people from all over the country for two days. We reviewed everything on *Mycobacterium avium*, microbiologically, pathologically, and clinically, and at the end of two days, Masur had a consensus document. There is nobody else that I know of who can take all these different people from all over the country and get a product in two days. If anybody needs to interviewed, it is Henry Masur. He is just incredible. He has endless energy, and his ability to coordinate people to work together is fascinating. He was responsible for bringing the initial working group together at the NIH. The only reason it broke down was because people were angry that somebody took a segment of the information that was yet to be published and published it themselves. But Henry is a mastermind at getting people together.

Harden:

We have talked with him. Dennis, do you have questions that you want to ask?

Rodrigues:

I noticed in your curriculum vitae that there was one paper in which you discussed working on developing a stain for *Pneumocystis*. Could you expand on that? Was there a problem in diagnosing *Pneumocystis*?

Macher:

It is very interesting. Early on, when we first started seeing lots of these patients, the Microbiology Laboratory was inundated with specimens. In fact, there is a three-day conference that is run by pathologists, this weekend, starting tomorrow, sponsored by George Washington University Hospital, which I will be attending. The chief topic will be the effect of HIV disease and AIDS on workloads, because microbiology and pathology laboratories around the world now are suddenly being inundated with specimens. When a patient gets sick, laboratories receive specimens of sputum, bone marrow, urine, stool, aspirations, and whatever from all parts of the body for just one patient. The laboratory has to do

bacterial, viral, mycobacterial, and fungal cultures, and look for parasites. So this is overwhelming the laboratory, and very early on, we were looking for different and more rapid methods to detect these different organism in these specimens.

I like to tinker and I was tinkering with these different stains. I am glad you brought this topic up because that was an interesting time in my life. There I was in a laboratory mixing different solutions and trying to find organisms that I knew were there, but I wanted to bring them out so that they were easy to see. In those early days we realized that what looked like a background of ghost-like material-it did not stain very well-was actually the *Pneumocystis* on some of these early stains. We brought the Pneumocystis out using methylene blue and other techniques just to highlight the organisms. Now, as it turns out, monoclonal antibodies are available that are even better for detecting Pneumocystis and other organisms. But early on we were very interested in helping microbiologists and technologists find these organisms rather rapidly and easily. That is what we became involved in. Again, those were very exciting days because we were literally mixing solutions just like you see on television. You mix blue and green and pink. We were trying to make the best solution possible to bring out these organism.

Harden:

What finally convinced you that AIDS was a communicable disease and when, if you can remember?

Macher:

That is a good question. I think fairly early on when Waldmann's patient gave us the information that two of his consorts in Haiti had died recently of terrible illnesses; even back then we thought that there was something that was being communicated, at least homosexually. Then, when we started to see the intravenous drug abusers, we suspected that this was just like hepatitis-B and the communication goes both ways. Then we started hearing about the bisexual men and eventually about the children. So very early on, we were concerned that this disease was being transmitted heterosexually, homosexually, and parenterally, and then, eventually, vertically from the mother to the child.

When we saw the hemophiliacs—in fact, the first hemophiliac that I saw was in Ohio. I was asked to give a lecture out there and the people there happened to have a hemophiliac on the ward. He was just 19 years old, and I sat down and talked to him for a long time. He told me that he had never had any homosexual activity, and it was very straightforward. The main thing we learned early on was not to be judgmental, to be very casual and open in our discussions. Even though when I came back to Washington, some people thought that this hemophiliac might be a closet

homosexual, I did not think so. Then, when I heard of more and more hemophiliacs who were getting sick, I thought it was probably from factor concentrates.

I remember the first meetings in Washington when that was brought up. There was great consternation amongst the blood bank people and the factor concentrate people because they would have to start preparing their concentrates in a different way, which meant money. It would cost more. So there was great consternation. "Are you telling us that this might be in the blood supply or in the pooled products?" And yes, it was.

But it is interesting that you asked, and I guess that it was with our first case that we worried about that.

Harden:

Even that early? We have seen that somewhere in mid-1982, when the epidemiological data finally started to build up, the people concerned with the blood supply took a very conservative approach to the whole thing. It was not just the money, I think, although that certainly was a major factor, but when a great structure is in place as to how something is done and when it starts to be altered, you need to make sure you know what you are doing before you do it. That was the basic argument that they were making.

Macher:

You can see what happened in France. In France, the law suits are ongoing until today because, as you say, it was a tremendous effort to switch from the process that was being used to heat treat a product. It took years in some places to institute that. The amazing thing about this disease is how much was learned very early on, especially if you look at the history of medicine. Look how long it took to figure out tuberculosis. It was hundreds of years. It is amazing how quickly information on AIDS was pulled together.

Harden:

We came across a very sad thing in some memos to the NIH in the fall of 1982 from the mother of a hemophiliac. Bob [Dr. Robert] Gordon answered them. "Is my child in danger? We have struggled so." That must have been wrenching for a physician dealing with the patients to handle that part of it at the same time as he or she was trying to figure out the science.

Macher:

Yes, I think there were some very tough moments in those days. When you were in medical school, you had learned how to deal with cancer, diabetes, and heart disease, but AIDS was different. Even though at the NIH we were doing consultations on the cancer floors all the time, there was something different about this new disease. Psychosocially, for some

reason, AIDS made a much greater impact on most of the people with whom I was working. We were seeing people die very quickly. Psychologically, for many of the health care workers this was difficult, we were not used to this. With the cancer patients, we gave them chemotherapy, radiation therapy, and steroids, but many of them lived for years. In fact, patients with Hodgkin's disease were even cured, and children with acute leukemia were cured. The little boy with *nocardiosis* had acute lymphocytic leukemia. That is a type of leukemia you can cure. So if you can treat the opportunistic infection, the *nocardiosis*, you can get the patients through.

But this disease was different and even Tom Waldmann's first case only lived from April to October. We had others who died even faster. As we were a research center, the cases were coming to us. Many of them were dying very quickly so it had a tremendous impact on many of the health care providers, especially when we went into the fifth, sixth, seventh, and eighth year of caring for AIDS patients. It is only now we realize that AIDS is a chronic disease and that it begins ten years earlier. If you think about it, our man in 1981 did not just get his infection a month or even two months earlier; he got it in the 1970s.

Harden: When did you start thinking of AIDS as a chronic disease?

Macher: When we first did the longitudinal studies. As you know there are cohort studies of homosexual men who have been followed for five, ten, and

fifteen years. Since these men's serum had been saved for hepatitis-B studies, when the data started to come out for AIDS we were able to go back and look at the serum to see if it was antibody positive for HIV. We first learned that we could actually tell which year the men became seropositive, when they developed lymphadenopathy, oral candidiasis, and frank AIDS. It was only from these cohort studies of male homosexuals that we first realized that AIDS was not something that just happens and a month, or six months, later the person is dead. The disease process goes on for ten long years. It was from those cohort studies relating to hepatitis B that we first realized that AIDS was a chronic disease.

Now, especially in our educational activities, we try to teach primary care providers that AIDS is indeed a chronic disease and these patients can be managed effectively for many, many years. When they do develop severe opportunistic complications, they can be referred to the experts, the infectious disease consultants. Our primary effort right now is to explain to these primary care providers, whether they are family practitioners or general internal medicine people, that they can take care of these patients for many years.

Harden: That is very interesting.

Macher:

This is a major effort because when somebody goes into practice and has a thousand people in their practice, it is difficult for them suddenly to bring in HIV patients for multiple reasons. Sometimes, if other members of the practice, both patients and providers, realize that AIDS patients are being brought in they may not come to that practice anymore. It is very difficult to convince those who have already been in practice for ten or twenty years to start seeing HIV patients for the first time. Many of us believe that the group that most needs to be educated is the new medical, nursing, and physician assistant students. There are still able to accept this as something that is their responsibility. If such students see the patients early on, when they go into practice they are more willing to continue to see them.

To this day there are certain physicians who refuse to see these patients. They tell us that and some say even worse. Our effort right now is trying to get information to the providers, showing them how to take care of these patients, both in the early, middle, and late stages of the disease, and providing them backup with infectious disease specialists who will give them proper information if the patient does develop serious complications. We are now developing networks. In fact, on March 4, 1993, we announced that the first nationwide 800 phone number was available for clinical consultations at San Francisco General Hospital. We help support that consultation service. As they get about thirty phone calls per day, they are very busy.

Harden:

Is this for primary care physicians who are treating AIDS patients to call in and consult?

Macher:

Yes. For instance, they call me in on the difficult cases and we talk about them. Florida just called them last week about a patient with *mycobacterium kansasii* pneumonia and they wanted to know if that patient should be isolated like a *mycobacterium* tuberculosis case and we discussed that. So people are calling in about anything related to HIV care, especially about doses of drugs and interactions of drugs. Imagine a patient who is on twelve different medications. You start worrying about interactions, side effects, and excretions. The 800-line that we have at San Francisco General Hospital has clinical pharmacologists available amongst its faculty consultants. There is no other service in the country, or the world, that can provide "warm" line information with backup from clinical pharmacologists.

Harden: That is a project of the Health Resources and Services Administration?

Macher: Yes. I can give you literature on that as well. It is an exciting project

because it is very labor intensive. Imagine that the working hours of the people involved, Pacific Coast time, are from 7:30 in the morning to 5 p.m., which means on the East Coast from 10:30 a.m. to 8 p.m. The consultation service is getting calls from all over the country and the queries can be about anything. They take a history of the patient and they listen to the questions. If they do not have the answer immediately, they do consultations among themselves and call back. If they are too busy to take the call immediately, people can leave an electronic message and they call back. That is why it is called a "warm" line. A hotline means that when a person calls in someone is always there to answer their question. During 1985-1988, when I served as Director of the Collaborative Center for the Investigation of AIDS and Registrar of the Registry of AIDS Pathology at the Armed Forces Institute of Pathology, I ran an 800 hotline because I knew that pathologists were having a lot of difficulties with this new disease as they had to diagnose unusual opportunistic infections such as microsporidiosis, cryptosporidiosis, toxoplasmosis, and progressive multifocal leukoencephalopathy. Those are conditions that pathologists are not used to looking for. I had four pathologists, five days a week, including myself, to answer the 800 hotline. It was incredible. We heard about cases from all over the country, from all over the world. People would Federal Express biopsies to us because they could not make a diagnosis. We would cut the specimen, and stain it, to make a diagnosis.

I want to come back to this topic, but I wanted to ask Dennis if he had any other questions he wanted to ask before we move on.

You indicated that very early in your career you had an interest in politics and law, so perhaps you were attuned to what was happening politically. I always find it interesting to ask some of the people who were in the trenches how they viewed what was happening politically with the rise of

the gay rights movement and its harsh criticism of what was happening in the administration and in the Public Health Service. How did those people who were actually dealing with patients view the political firestorm that

was raging about the disease?

That is a very interesting question, but we were so inundated, seven days a week, twenty-four hours a day on call, that it did not really affect us. We were always in the hospital taking care of another emergency. I think what was happening affected the bureaucrats more than the primary care providers. The gay rights people were not angry at us, they were not saying we were not taking care of the patients; they were angry at the

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Harden:

Rodrigues:

Macher:

bureaucracy. We were so busy that it never really affected us and we never got involved in that. In fact, I remember someone once told us that they actually marched on the FDA [Food and Drug Administration], here at the Parklawn building, and threw some stones through the windows. But we were so far removed from that. We were not bureaucrats. We were taking care of the patients. We never felt that they were angry at us.

Harden:

On a personal level though, if I can take this one more step, a nurse to whom we talked said that her sons did not want to have to say to their friends, "My mother treats AIDS patients," because there was some fallout. People would worry whether she had AIDS or whether she could give it to them. Did you have any personal repercussions in your family or elsewhere?

Macher:

No, I was never in a situation where either friends or family said, "That is terrible" or "That is disgusting." I was always in a supportive atmosphere where people said, "At least someone is doing it." People were grateful that somebody would actually try to help the patients. Again, I am sure that some people were in positions where what you have just described occurred, but we were too busy. In fact, with the *Military Medicine* series that I was putting out once a month, of cases for diagnosis, I had a thirty-day deadline for three years. I was writing up these cases all the time, and making all those presentations. Again we were too busy. We just did not get involved in the firestorm, and it was a firestorm, because we were doing the work. I think the bureaucrats were taking most of the firestorm.

Harden:

I wanted to talk a little more about your time at AFIP [Armed Forces Institute of Pathology]. First, I wanted to ask why you decided to go into that and get out of the situation at NIH where you were doing so much direct patient care.

Macher:

NIH works on a pyramid system and after you finish a residency or fellowship, unless you become a senior scientist, you go on to somewhere else. At that point in my career I was not going to be a senior scientist and the opportunity arose for me to start a registry of AIDS pathology at the Armed Forces Institute of Pathology, which until then had their AIDS cases sort of scattered under people's desks. The AFIP has, I believe, about forty different branches. OB/GYN cases are in OB/GYN even though it might be an AIDS case. That is the branch it is in. But pulmonary cases are in the Pulmonary Branch, the brain cases are in the Neuropathology Branch. Nobody was taking all of the AIDS cases and putting them in one place.

Harden:

What does a registry mean? Could you explain that a little more.

Macher:

For instance, there is a registry at the Armed Forces Institute of Pathology of obstetrics and gynecology. If you want to know everything there is to know about ovarian tumors, you go to that registry and they literally have an example, pathologically, grossly, and microscopically of every known ovarian tumor. Or of every pancreatic tumor which is in the GI registry. But there was no registry for AIDS. Since I was trained both in infectious diseases and in pathology, it was a good place for me to go to. I could take the clinical histories and rewrite them, take the pathology slides and study them to the umpteenth detail. We literally took every organ and did every stain on every organ. Now when you do an autopsy you do not have that luxury. You are lucky if you are in a medical examiner's office if you get specimens to do one stain. You might be able to do it on a couple of different organs. I did every stain on every organ. It was very labor intensive but that is what the AFIP was into, studying the pathology of anything.

I wanted to define the pathology of AIDS and that is why the book came out that you saw—AIDS: An Atlas of Cases for Diagnosis (Macher AM; 1988)—it is a color atlas. Since we had the funding we did the gross pathology and the microscopic pathology in color, and we started to put together one of the first atlases. I wanted people to see in color, not in black and white because it means nothing in black and white, to realize what this disease could do. For me it was a natural stepping stone to go to the AFIP at that particular time, especially since I had already spent a year there earlier in the 1970s as an infectious disease fellow and I was familiar with the building.

I do not know if you have ever been to the AFIP but it has no windows in a certain part of the building because of concerns that if an atomic bomb were dropped on Washington the archives of all this pathology should not be destroyed. So the older part of the building has no windows and has lead and steel for feet at a time, and I was in one such part of the building.

Harden:

I am trying to recall just when it happened. Were you there when you were the consultant on the AIDS exhibit that the museum developed?

Macher:

Dr. [Mark] Micozzi put together a plan to have an AIDS exhibit. I put up some of the actual cases that we were seeing onto panels in color so that people could see how the patients were presenting and how we worked them up pathologically. I guess that was the first AIDS exhibit they had ever put together.

Harden:

That was a good exhibit.

Macher:

Thank you. Much credit should go to the people at AFIP because they had the foresight to do something on AIDS. As you know, the military has mixed emotions about AIDS. Early on they did not want to do anything, but the AFIP thought it was an important project. Young children come through there all the time to look at the Civil War exhibit, and they would thus also be exposed to the AIDS exhibit. I think it took a lot of courage to put the AIDS exhibit adjacent to the Civil War room—it is an open area. From the very beginning I thought it was important to educate children about this new disease. The AFIP did a fine job. This whole process of the oral history is interesting for me because you are bringing back many memories. We are so busy that we do not really have time to recollect on things like this.

Harden:

In the course of this interview, if you think of additional things you would like to discuss feel free to do so. In 1988 you moved into your current position. As I said before we started, we would like to have an overview of what you are doing now, not only the conference calls but other things that you think it is important that we record.

Macher:

What I have been doing for the past four years is to serve as the medical consultant to the AIDS Education and Training Centers. What I am basically doing is taking my entire experience from the NIH, from the AFIP, and educating primary care providers about HIV disease and AIDS. Because of my clinical pathological perspective when I evaluate educational training programs and when I do my own programs, I have a little different perspective. I want people to understand that the patients whom they will see for the first time have probably carried the virus for a decade in many cases. When they become sick they do so because of this pathophysiological process. I explain why the patients are having fevers, why they get oral candidiasis, why it hurts in the right upper quadrant, what our experience has been. When the patients present with headache, I explain what are the causes of headache that I have seen.

Yesterday, at the Society for General Internal Medicine's national meeting, the case of a thirty-one-year old man who had stabbing pain right below the right eye was presented. When a CAT scan of his sinuses was done, it was negative, but something was causing stabbing pain. We talked about how you work up such a patient. You go the next step with an MRI scan. It is more expensive but that is what you do next. Sure enough the MRI scan revealed a lesion, not near the eye but in the brain stem, which conferred pain. So I talk about it not just as a clinician but as a pathologist. I explain what it looks like inside not just on the outside.

As I told you, I will be going up to the Pennsylvania Department of Corrections because I do a lot of work in the prisons. The prisons right now are the petri dish for this epidemic. As you have seen on television, there are many problems in our nation's county jails, state prisons, and federal prisons. Tuberculosis is there, HIV is there. Even though letters from Charles Colson to the editor of the *Washington Post* state that in his experience in prison the omnipresent guards do not allow sex or drug use to occur—that statement is false. I do not even know why they let him publish that letter.

I have been in prisons. Do you know what a cell block is? It is a corridor with two floors of cells on each side and it is very long. I have been in cellblocks built for 400 people that have 750 in them. Everybody is smoking cigarettes and you cannot see half way down the cellblock. It is full of smoke and crowded with people. When you ask the correctional officers who are at the front of the cellblock, "Can you walk me through there?" they say, "No, I don't think it's safe." If you ask them casually, "Do you think illicit activity is going on back there, because look how crowded it is," they will answer, "Oh, sure. They are having sex, and they are shooting drugs." That is where the HIV epidemic is right now and that is where the tuberculosis epidemic is. These men that are coughing in each other faces could have a cigarette cough and chronic lung disease, but it could also be tuberculosis.

Just last month in a prison in our area yet another prisoner who was HIV positive was released to a local homeless shelter. The shelter was assured that he had been worked up for tuberculosis even though he had a cough. He spent twenty-nine days in the homeless shelter. He had pulmonary tuberculosis, multi-drug resistant, the worst kind. Again, the system has broken down. There is no continuity of care for these people. One of our major efforts right now is to get into these county jails, state prisons, federal prisons, and teach the primary care providers what they need to know about HIV disease and tuberculosis.

Harden:

Now I want to ask a speculative question. I have this notion in my head that many primary care physicians today are treating upper middle-class homosexual males who were infected ten years ago. I have also in my head the idea that five, ten, or fifteen years from now those are not going to be the patients. The patients will be prisoners, the homeless, and so on. Who is going to be interested in AIDS? What will happen at that point?

Macher:

Yes, the inner city Hispanics, African Americans, whoever is in the inner cities right now, in Newark, New York, Houston, Miami, Cleveland. Yesterday a private practitioner ran a workshop. I believe he has 100 HIV

patients in his practice and the majority of those patients are middle- and upper-class male homosexuals. Somebody asked him, "Who is seeing the drug abusers, the women, the prostitutes, the children, etcetera, who don't have insurance?" He said he does not see such patients because, first of all, they do not show up routinely so they disrupt his practice. Instead he sends them to the public health clinics. That is where the epidemic is right now. It is in our community health centers, migrant health centers, rural health centers, public health units, and emergency rooms.

As you know, our inner city people use the emergency room as their primary care provider. Not a week goes by without my hearing another story about somebody showing up in the emergency room for HIV care, because they do not have a primary care provider they can turn to. You cannot clog emergency rooms for HIV care. The question now, for the new administration, is how do we correct the system. How do we redistribute care? It is very expensive. You have to educate primary care providers everywhere on how to do this. That is also expensive and it is all labor intensive. This does not occur overnight and that is the dilemma. In the homeless shelters in many large cities, a good percentage of those people have HIV and are infected with tuberculosis. It is just a matter of time before the latent tuberculosis that they acquired years ago reactivates as their immune system gets weaker. They start to cough, and they infect other people. This again is a very labor intensive, economically costly endeavor. That is the problem right now with the HIV epidemic.

You are right that the middle- and upper-class male homosexual has access to care. The rest do not. Every week we ask ourselves what is it going to be like in the year 2000. At every conference this is talked about. There are projections, and they show that upward slope of the curve. But, at the same time, the government is putting out these "Healthy Year 2000" objectives that seem in conflict with the reality that tuberculosis is on the rise, HIV has not disappeared, and gonorrhea and syphilis are occurring. Yet "Healthy Year 2000" says by then 99 or 95 percent of the people will not have these problems. Two branches of the government seem to going in two different directions. Somebody is writing these "Healthy Years 2000" objectives saying that we going to cure this and cure that but the reality is how can someone be cured if he or she does not have access to care. It is a dilemma and almost an oxymoron.

Harden:

Is there anything else that you would like to say before we end the interview? Is there anything that we have missed or that you think is important to get on the record.

Macher:

No, I think we have covered a lot of issues and I thought you did the

interview very well. You brought up a lot of provocative points and I found it very interesting myself.

Harden: We thank you very much.