# INTERVIEWEE: Dr. Catherine Wilfert INTERVIEWER: Jessica Roseberry PLACE: Dr. Wilfert's home in Chapel Hill, NC DATE: August 25, 2006

## WILFERT INTERVIEW NO. 1

JESSICA ROSEBERRY: My name is Jessica Roseberry, and I'm here with Dr. Catherine Wilfert. She's professor emerita of pediatrics and microbiology at the Duke Medical Center, and she's also the scientific director of the Elizabeth Glazer Pediatric AIDS Foundation. It's August 25, 2006, and we're here in her in her home in Durham. We're actually not in Durham, we're in Carborro. Is that right?

DR. CATHERINE WILFERT: We're in Chapel Hill.

ROSEBERRY: Chapel Hill. Okay.

WILFERT: Orange County.

ROSEBERRY: In Chapel Hill, North Carolina. And I appreciate your willingness to be interviewed today, Dr. Wilfert.

WILFERT: It's a pleasure.

ROSEBERRY: It's a wonderful opportunity. I thought I might start by asking you just, kind of, some of your early influences to go into science, if that's all right with you.

WILFERT: You mean when I was a child?

ROSEBERRY: Sure. Or teachers. What influenced you to go into science?

WILFERT: Well, my folks were schoolteachers, both of them, elementary and junior high school teachers, and education of one kind or another, whatever you chose to do, was always important for them. And in particular, it was of an era when my maternal grandmother thought

boys should be educated but not necessarily girls, and so my mother grew up her whole life saying, "It's not going to matter whether they're boys or girls, they're all going to school." So they were very supportive of whatever we wanted to do. I don't really know why I chose to be a physician. I had an uncle who was a physician, and I admired him, and I always liked science and I liked people, and it seemed like combining science and people could be done easily in medicine. I had a lot of good teachers along the way, but I think it was my selfish interests or enjoyment of science that really pushed me there.

ROSEBERRY: Did you enjoy research? Did you enjoy that aspect?

WILFERT: Like most people, when I started I don't think that I knew enough to know that being a physician opened doors into research or into public health or into taking care of patients. But I learned that as I went along, and I came to enjoy research. But I didn't know that from the beginning.

ROSEBERRY: Okay. Now, you got your medical degree from Harvard.

WILFERT: I did.

ROSEBERRY: Can you tell me a little bit about the atmosphere there?

ROSEBERRY: Well, you know, it was a long time ago. It was in the fifties and early sixties, so they never admitted that they had quotas, but it seemed like there were seven women in every class for years. And so there weren't very many women in medical school at that point in time, and most of the hospitals and facilities didn't know how to—didn't have facilities to accommodate them. So if you were in the hospital overnight, they had places for men to sleep, and they didn't have places for women to sleep. There were not bathrooms for women. There were just a lot of sort of logistic items that people hadn't exactly thought about, but it was not insurmountable. They treated me fairly, I thought, and so it was fine, and it was a lot of fun,

actually.

ROSEBERRY: Okay. You eventually ended up at Duke in 1969, I believe.

WILFERT: That's right.

ROSEBERRY: I wonder if you could tell me some of your impressions of Duke when you arrived.

WILFERT: Well, I came from Boston, and so Harvard was a huge system, and actually it was so different. I mean, I'd gone to medical school and worked most of my postgraduate years in Boston, so I didn't understand other systems particularly, and coming to Duke was just a real pleasure, because the undergraduate institution and the medical school were on the same campus. It was contained in a reasonable physical space, so collaborations were encouraged, but also easy because the scientists that were elsewhere on campus, it's from one building to the next. It's not across the city, and that was very different. Harvard's undergraduate campus is obviously in Cambridge, so basically you didn't have anything to do with the undergraduate campus, and the medical school was next door to the Brigham Hospital, but all the other hospitals were scattered all over the city. So although—I think Harvard wouldn't like this—it was like it was a two-year medical school, because you had classes for two years in one campus, and then everybody dispersed to the clinical facilities. So if you were living in the dorm, you mixed and saw people, but otherwise it was ins and outs. And so Duke was a welcome, refreshing change first of all because of the collaborative nature, and secondly because of the proximity of folks on a single campus. It was really fun.

ROSEBERRY: Can you tell me about some of those collaborations that you were talking about? WILFERT: Well, I was appointed in the Department of Pediatrics, but I was placed in the midst of microbiology, in the laboratory, so the collaborations were kind of obvious. I mean, we were

all next door to each other, and I derived a lot of benefit from the folks in Microbiology helping in the laboratory things. Within the Department of Pediatrics it's hard to remember all of the things that happened, but you could work across Pediatrics and across Medicine as we did. There's infectious diseases in Medicine, and there's infectious diseases in Pediatrics. We shared conferences, and we shared clinical work and research. It was just easy. It just happened every day, and you didn't much think about it.

ROSEBERRY: Yeah. Good. I wonder if you—do you remember some of those people that you were working with in some of those early days?

WILFERT: Well, some of the people who aren't there any more, obviously, because a significant number I'm afraid have passed on with old age, but David T. Smith was in Microbiology. He was a tuberculosis expert. He was always at the conferences, and sharing information and things. Dr. [Norman Francis] Conant, who was a mycologist, likewise was at the conferences, and helped to run the mycology laboratory. There's a pathologist, Dr. [Bernard] Fetter, who—you know, you gravitated to the people who were good teachers and enjoyed working in those areas that are related to infectious diseases, so we had a lot of nice contact back and forth. And Dr. [Wolfgang K.] Joklik, the former chair of Microbiology, was a wonderful person to work with, as were the people in his department.

ROSEBERRY: What about some of the people in Pediatrics? Do any of those stand out to you? WILFERT: Oh, there were lots of—I liked almost all of the people in the department. It was very small when I came.

### ROSEBERRY: Okay.

WILFERT: I don't remember. Sam, Dr. [Samuel L.] Katz, would remember how many people there were, but I don't think there were more than a couple dozen faculty in Pediatrics. And now

there must be almost a hundred, so the department and the medical school has grown, but the department has grown a lot. The people in Pediatrics always included folks like Debbie [Deborah W.] Kredich, who recently passed away. She was in Rheumatology. And Lois Pounds, who's still here. She was in the outpatient clinic, among others. Just a lot of really nice people.

ROSEBERRY: Okay. Good. Well, what were some of the infectious diseases that you were working with at that time, or that seemed to be the most common or prevalent? WILFERT: Well, things sort of, you know, you need to deal with whatever the problems are, and an awful lot of the work that I did was patient based, so it would happen-I think I worked together with Becky [Rebecca H.] Buckley—we had a group of children who had a congenital problem with their white blood cells. They couldn't manage infection well. It's got a name: chronic granulomatous disease. So we worked together with those families, because they had a lot of infections, and because she was working on finding out what was the matter with their white cells. It was relatively new at that point in time. There weren't very many kids known. And we had a huge family of folks who were unfortunate enough to have it, so that was one of the things that happened early. North Carolina and a lot of the southeast has tick-borne diseases, so Rocky Mountain spotted fever was, in fact, a common-relatively common problem at the right time of the year. So we did a lot of work on Rocky Mountain spotted fever in the early days. Because my responsibility was running the virology laboratory, I got to see or learn about a number of the infections that folks had in enteral viruses. Like polio and ECHO [enteric cytopathic human orphan] viruses came to be part of the work that we did in the lab, and again, we observed that the kids who are congenitally deficient in antibody had a lot of trouble with those infections, and they can't get rid of them. So they can have a chronic central nervous

system infection, and I think that collaboratively that was one of the things that we described that people didn't know about before. That was fun. Again, that's Becky Buckley and all the folks in pediatrics. It was exciting when you were both enjoying answering questions and the people you worked with. It was a lot of fun.

ROSEBERRY: You were talking about working on some of these things in the lab, and I'm not a scientist, so that sounds very exciting and somewhat mysterious to me, and I wonder if there's a way that you could talk about that to me in layman's terms. What was the process like? WILFERT: Well, the job was—probably more familiar to most people is the bacteriology laboratory. If you want to know if you have a strep throat, you can send a culture to the laboratory, or, these days, do a quick test, and people sort of take that for granted. Some magic happens in the laboratory to grow the bacterium. Well, the virology lab is similar. It's just harder to grow the viruses, because they like to grow inside cells. They don't just grow on odder plates, so running the virology laboratory and trying to determine (a) if there was a viral cause for an illness and (b) what was the virus was—it's like a mystery story. You're just starting to put the pieces of the puzzle together within the context of growing viruses in the cells in the lab. ROSEBERRY: Okay. Well, it sounds like the department was fairly-you've mentioned some women in the department, and it sounds like that was a pretty welcoming place for women to be. Was that true in your experience across the medical center, or particularly in Pediatrics, or were there—?

WILFERT: I think particularly in Pediatrics. I think that much more so than other departments, and I know it's evolved with time, but I think Pediatrics had fifty percent faculty members that were women way before other departments did. It probably had, I'm sure, more women residents and more subspecialty fellows as well. A lot of that is because Dr. Katz felt that was

important, but it's also at a time when medical school classes were shifting so that many more women were accepted into medical school. But it's still the case that in some departments in many institutions, although thirty years has gone by, it's not balanced with regard to gender in the senior faculty ranks yet, still. That's the way it is. But Pediatrics was trying. Was accepting, really. There were lots of fine women to have jobs, and so it happened.

ROSEBERRY: Were there other women across the medical center that you can think of whose names were important as someone might look back and think about important women in the medical center, and whose names might need to be recorded for posterity?

WILFERT: Well, there was a general pediatrician at the same time whose name was Shirley Osterhout, and her husband ran the microbiology lab in the early days. And there was a woman in the Department of Medicine whose name was—she was Dr. [Jerome S.] Harris' wife, Jackie Hijmans, I think, and she did internal medicine. I'm just trying to think. I'm sure there were more in basic science that I am not appropriately remembering. Oh, there was in Microbiology, Hilda [Pope] Willett was one of the first. She was an early PhD student at Duke, and she was a professor in the Department of Microbiology. She was a very fine person. She used to live in Raleigh, and I've lost total track of her, so I'm not sure where she is. [*computer makes noise*] ROSEBERRY: Should I put on pause for a minute?

WILFERT: No.

ROSEBERRY: Okay.

WILFERT: I just need it to start up again.

ROSEBERRY: Okay.

WILFERT: I'm through with it.

ROSEBERRY: Okay. Great. Well, I wonder if I can ask about Dr. Katz. Did you two come to

Duke together?

WILFERT: Not really. He came in 1968, the year before I came, but we did both come from Boston together. I mean, each of us came from Boston, and we got married after I'd been here for two years in 1971. I suppose it goes without saying that he was in the process of a divorce, as was I when I moved here. It was not because of each other. It was independent circumstances, and we came to Duke and subsequently got married.

ROSEBERRY: He became the chair of the department, and I wonder if—I hope I'm not asking you to speak for him.

WILFERT: No.

ROSEBERRY: But I wonder if you could talk about kind of the direction of the department as he was the chair?

WILFERT: Well, when he came, there had only been two preceding chairs, Jerry [Jerome] Harris and Dr. [Wilburt Cornell] Davison, and he came as a young man. He was in his early forties, I believe, and it was time for the department to grow and expand. So that's what happened when he came. He got more faculty, and the department grew, and the research efforts of the folks in the department expanded very naturally. So it was fun, I think, to be part of something that was growing in a nice way. It's often the case, I think, in institutions that do different things like a general hospital—kids don't vote and kids don't speak for themselves, so the folks who take care of kids naturally are advocates. And within the context of a university medical center providing care for children is not as remunerative as some other aspects of medical care. It's not like procedures, for example, for many subspecialties, so supporting a department of pediatrics requires a lot of advocacy on the part of the faculty, but it also requires an understanding dean and people in charge, because it means that there may need to be some

special considerations if the department is going to be viable. If all of us worked full time and took care of children, I think it's doubtful we would support the other activities in the medical center. You just don't get enough money back to do that. So you have to have grants, and you may need donations. That Children's Classic golf tournament has provided money now for over twenty-five years for the Department of Pediatrics, which has been an enormous help. But it's kind of a struggle. Because the ability—until you have a high academic standing, you're still small in numbers. At one point in the early days, there were more cardiology fellows in the Department of Pediatrics. So you felt like, you just knew how small you were in comparison to the rest of the machine.

ROSEBERRY: Do you think that has something to do with each other, the lack of funding, maybe, and how big the department was?

WILFERT: Well, yeah. I mean, but you need support from your institution. If you're responsible for teaching medical students a substantial part of your time, you can't be seeing patients at the same time. So it's reasonable to think that the teaching activity is paid for, but by whom? Not just the patient fees that you take in, which, these days, certainly wouldn't be allowed to do that, and it's an unusual grant that provides funds to teachers to teach. So I think that's an important collaborative effort on the part of the institution. If adequate support isn't provided, then people become—they are committed to, and need to take care of children, and become consumed by efforts to provide care, and you don't have enough faculty members to do the other things. Recognizing that other people may have different perspectives, I don't think a medical school can be an excellent medical school that doesn't have each of the major parts: take care of children, take care of women, deliver babies, do surgery, have internal medicine. I

mean, you can't just say, Well, why do we have pediatrics anyway? It's losing money. Shall we do away with it? I think most people would say that would be stupid. But it requires extra support.

ROSEBERRY: Do you feel like Duke offered support for that?

WILFERT: Sure; I do. I don't know what's enough. You always want more, but I do feel like Duke offered support. If you work for a state institution like UNC, which is a fine institution, you get a given amount of your budget from the state every year. It may not be enough, but it's a fixed source of income. A private institution like Duke doesn't have that, not from the taxpayers, and yet I think Duke has always taken care of the indigent. We used to be, and I'm not sure about this any more, that we took care of larger numbers of indigent than any other facility in the state, but we don't get money from the state to do that. All these things are a balancing act, and fortunately, I think Duke put patient care first, and they would lean over backwards to try and be sure that people got taken care of. Kids and adults.

ROSEBERRY: Is pediatrics different medically than internal medicine?

WILFERT: Yeah. People get different diseases, and they are different, and there are a whole lot of different problems. A good example would be that if you have a lab to do blood tests, you're not going to get 10 MLs of blood from a baby in the premature nursery, and yet you want to do the test. Well, it is, in fact, possible to do it on very small quantities of blood, which requires totally different equipment in the hospital. So it means a separate lab. And actually, if I'm remembering this correctly, when we built Duke North, we asked that the hospital have all that kind of microtechnology. That there was no reason to take more blood from adults if you could do it on a smaller quantity, and then you could accommodate everybody in the hospital in the lab with a single lab. And the decision was made not to do that. We would have a separate pediatric

lab. And, again, I'm out of touch with it all, but it got to be the case that the people on Medicine knew that if they only had two milliliters of blood they could send it to the pediatric lab, and it wouldn't go to the regular lab. So it gradually was appreciated that it was silly. I mean, you didn't need to take large quantities of blood if you could do it on small quantities of blood, so I think most of it has been changed, in a way. But it wasn't in the beginning. We had to have a different, separate laboratory to do things on small volumes of blood. That's a "for instance." It's not particularly negative, but it sure did impact. It also is the case that the kinds of microorganisms, or the things that you're looking for in sort of routine cultures, are different in kids than in adults. They get sick with things that adults don't, and so if you're trying to run an efficient lab, and you make rules about, we'll only process these for *x*, *y*, and *z*, and then you have to go say, Excuse me. That won't do for this population. You need to look for *r*, *q*, whatever. And, you know, it worked out, but it's different. Every day it's different. And the values for some things are different in kids than they are in adults.

ROSEBERRY: The values? I'm sorry.

WILFERT: The laboratory values. When you get answers back. Kids are growing, and their bones are growing, and that's reflected in some of the chemistries that you do, and so the numbers are different. And blood cell counts is a very good example. The age shifts in, say, the number of lymphocytes that you have are very dramatic in the first four or five years of life. You can't use adult standard values for kids. You have to have pediatric numbers to assess the child by, and you have to be sure that your laboratory understands that, and is using the right values. Those are sort of everyday things that we take for granted, because they work pretty well now. But in fact, the HIV world woke up to that in a big way. Everybody knows CD4s now, and they know T-lymphocyte. Well, kids who are severely immunocompromised have higher

numbers of CD4 counts, and you can't tell that they're immunocompromised if you use adult values. Adults would use under two hundred, and for a child under a year of age, it's likely to be one thousand. And that looks like they're in really good shape if you use adult values. So people had to soak that up. They had to learn in the beginning, because they didn't know that, and once they learned it, they needed to make the appropriate adjustments. So I mean, there's lots of everyday life that's different about taking care of children. Not to mention you don't just walk in a room and say, Well, we're going to do surgery, and this is what we're doing it for. And it's a three-year-old. You have to talk to the parents in order to obtain permission and to have an understanding for taking care of the child. It seems very obvious, but the whole permission-consent process, and the considerations around the procedures, and things that are potentially dangerous are very different. And so you need pediatricians.

## ROSEBERRY: Can you remember when you first heard about AIDS?

WILFERT: Sure. It was in the early 1980s, and because I did infectious diseases, when the virus was identified it was clear this was an infectious disease. In the beginning it wasn't clear, but it was immunocompromise, which led to infections, so the kids came to be our responsibility anyway. So we began—the first child that I saw was probably in 1983 or '84, but I didn't know that's what the problem was with the child. The child had died in our intensive care unit, and when it became possible to do the blood test that identified HIV infection, we realized right away that there were a large number, a relatively large number, of infected persons in the Southeast. I mean, there were gay males for sure, but there was a lot of heterosexual transmission, and there was associated drug use and partners of drug users. So it was in the Southeast by the time I was involved with kids. It was more like what is in the developing world. That is, it was heterosexually transmitted. It was transmitted from mothers to their babies. And so we saw from

fifty to seventy newborns with HIV infection every year for a number of years, just adding up year after year. Now it's less than one or two for the state for the whole year, which is just really terrific.

ROSEBERRY: When you kind of saw those numbers increasing what were your thoughts? What did you do?

WILFERT: Like everybody else, we knew we were going to have to take care of them. We didn't have an infectious disease clinic in the outpatient clinic because infectious disease physicians were—at least in Pediatrics, were often taking care of illnesses. So that if a child had very bad chickenpox, for example, and was hospitalized, we would take care of that child. But most of the children with chickenpox were seen by their pediatricians or their general doctors wherever they were. So when the child got well who was in the hospital, they'd go back to their regular doctor. There were some illnesses that we followed, but there weren't very many. But as soon as HIV came along we had to establish a separate infectious disease clinic, and it was just full to overflowing with kids who needed special attention. And we built a network so that most of the kids in the state touched base at Duke at least, but many of them were followed at Duke. And we—ultimately, when we became involved in the Clinical Trials Unit, we could support other locations. And so some of the care could be transferred to Charlotte, and UNC collaborating, and some of the care could be transferred to the coast. But Duke led the effort to have kids taken care of in state. So we just needed to cope with it and treat them, and we did. And then through the clinical trials in 19—I should know this—1994, I think, when 076, which was the clinical trial sponsored by NIH, established that if you gave AZT to the mother during pregnancy, you could dramatically diminish the number of kids who were infected as a result of being born to an HIV-infected mom. And so that basically changed the epidemic for kids,

because if their mothers could be tested and take medicine, the kids had a greatly reduced chance of becoming infected. It was terrific. You know, it was horrible to live through the first years, because you couldn't treat kids at first. We just took care of them, and treated their other infections, and they died. And then it got to be possible to treat them and prolong their lives. It was like a miracle. They sort of came back to life. And then the treatment got better and better. And we could prevent infection, and that was the best part of all. So it's totally different now than it was twenty-five years ago.

ROSEBERRY: If I'm right, you became very involved in treating the mothers so that they didn't pass that infection.

WILFERT: Right.

ROSEBERRY: Can you tell me a little bit about how that came about?

WILFERT: Well, NIH sponsored a clinical trial network. One to treat adults. Initially, there wasn't a separate one to treat kids, so Duke was one of the first, I think, of three units that proposed to treat kids in the beginning. And that's an example of a good collaboration. Dani Bolognesi was the first PI [primary investigator] of the grant, and when I went to Dani and said, "How about kids?", we wrote part of the grant, and we got some of the money from the beginning to take care of kids. So that was a good collaboration, and it was fun. So putting everybody's brains together in the clinical trial units, people figured out what questions and trials they wanted to do, and we were extremely active in that regard. I think I'm more or less responsible for the idea that if you gave AZT to mothers, it might stop transmission to their babies. And that was a clinical trial which was done and was successful. Which was great. It worked.

ROSEBERRY: So what were the numbers? Do you know?

WILFERT: The reduction in transmission was about two-thirds, basically. And in the US it was possible to have mothers not breastfeed, so the babies were no longer at risk after they were born. Because they could get formula replacement feeding. But it just dramatically reduced the amount of infection, and the additional antiretroviral agents have reduced it even further. So now all of the other considerations--the reduction is, I think, probably one or two percent of babies acquire infection from their mothers altogether. So not quite a hundred percent but ninety-nine.

**ROSEBERRY:** Great.

WILFERT: Yeah.

ROSEBERRY: It's wonderful. That's great. Well, it sounds like Duke was pretty active in this fight.

WILFERT: Yeah. We were, actually. We were active in the state, but we were also active nationally, because we were one of the first units funded. So we worked together with the folks all over the country, but we had a head start.

ROSEBERRY: I do want to go back to that clinical trail. Can you tell me a little bit more about kind of going into that time when you were discovering that this was something that could impact children?

WILFERT: Well, all these things are complex and contributed to by a lot of folks. We had one drug, AZT, and we knew that it altered mortality in adults. And we came to know that it worked similarly in children. So that leads, I think, to the question, Will it prevent infection? I mean, it can stop the virus temporarily from multiplying, but if you give it to people, like mothers who are pregnant, who might pass the virus to their babies, either when the baby is in the womb or in the process of being born, will having the drug around prevent the baby from being infected?

It's not a given. You have to ask the question. And in the process of asking the question, FDA had a hearing. It's the only time I've ever been asked to discuss something before they would let you do a clinical trial, but we did. It's interesting when I look back on it. If you think about the potential toxicity to mothers, or the potential toxicity to an unborn baby versus giving them a drug, and you don't know those kinds of consequences versus hoping that it will in fact diminish transmission. And I think everybody realized that if you had HIV infection, unfortunately your life was going to be shorter than if you didn't have that infection. And we knew virus could be passed from mothers to their babies, so it was worth the risk of asking the question when the drug you were giving the mom was good for her. It would prolong her life. So if it happened to hurt the fetus, that would be sad, but it wouldn't be a total negative. So people were willing to take the chance and design a trial, which got a lot of publicity, where some women got nothing, some women got AZT, and see what the transmission rates were in the two groups. And we were two-thirds lower in the ones who got AZT, and there's no harmful consequences. (*sound of telephone ringing in the background*)

WILFERT: Forgive me. Hello. I'm sorry but he's not here. Yes. You're welcome. That's the problem with being home is all the solicitations.

ROSEBERRY: Oh.

WILFERT: That would be the Democratic National Committee.

ROSEBERRY: Let me check we've got this off of pause. It's not giving a sign, which is unfortunate. I'm going to—. Okay. I'm sorry. You were talking about that clinical trial. WILFERT: And it worked, and there was no harm to the babies or the moms.

ROSEBERRY: Great.

WILFERT: So it was really exciting for everybody. I did not personally do the clinical trial.

Dr. Ed Connor, formerly of the University of New Jersey who now works for Meadowview, actually was the person responsible to guide the trial in the clinical trials unit. My responsibility was to head up the whole thing for a while, so I participated by proxy, and we enrolled patients at Duke.

ROSEBERRY: And you mentioned that it got some publicity. Was it good? Positive or negative?

WILFERT: It was positive, but it began a whole cascade of negative publicity because—you may not—most people wouldn't be tuned into this, I guess. People wanted—we knew there was a lot of disease in Africa, but we also knew that there was no way that women were going to get AZT from the first trimester in their pregnancies, throughout pregnancy. That it wasn't as simple as saying, Well, we have a drug, and so here it is. Please use it. First of all, I now understand completely, and I really didn't know then. I knew enough to say that this isn't going to work. They don't come in early in pregnancy for antenatal care usually. They come second trimester in some places, but third trimester in many places. They don't come back regularly. People didn't know how to use antiretrovirals, and the initial cost of AZT was prohibitive. It was on the order of eight hundred bucks for a single woman to be managed in the United States. But when your health-care dollar in the developing world could even be as low as a dollar year per person, no way that people were going to have access to a drug that expensive. So trials were designed. Thailand was the first one, and I think that trial was done with four weeks of AZT. Instead of starting in the first trimester we started at four weeks, hoping that that would be a more feasible regimen in the developing world, and it worked. And they also did the same thing in the Ivory Coast and Burkina Faso. And it worked, but there was additional transmission from breastfeeding over the next eighteen months to two years. But it still reduced transmission.

Well, those studies were also done by comparing four weeks of AZT to nothing. And there were folks who felt very strongly that that was not an ethical trial. You had compare four weeks of AZT to—whatever, twenty-eight weeks of AZT or thirty weeks of AZT. I understand what they're saying. On the other hand, that was not available and wasn't the standard of care in the situation in which this was being tested. And if you compared those two, I mean, this is sort of the structure of clinical trials. If you opted to do that just because you thought you would need to do it, the size—the numbers of women that you would have to enroll to compare two treatments is a whole lot larger than if you compare a treatment to nothing. Because in order to demonstrate that there's a difference, you just have to have a whole lot more women. Suppose posttransmission was reduced by two-thirds in one, and by fifty percent in another. You can't demonstrate that in two hundred women in an arm of a trial. So the ethicists screamed and hollered and complained that we were abusing-I wasn't involved in those trials, but that the developed world was abusing folks in the developing world. And no matter how you explained about the balance or how you explained that you could get the wrong answer if you didn't compare, especially with the complication of breastfeeding, it still got enormous publicity. Every place from The New England Journal of Medicine to every place else. Actually, my claim to fame may be that I resigned from the editorial board of *The New England Journal of Medicine* over this fight, because the editor wrote that the trials in Africa and Thailand were not ethical and put it out there. The scientific world responded vigorously, but she wrote this editorial, and it certainly wasn't reviewed by anyone on the editorial board. And that seemed like if you have a group of people that you've brought together to think about how to improve the journal or to help the journal, that it would be considerate to let people know that you were going to unleash this on the world. So several of us resigned. It's weird. I got more phone calls and more mail

about resigning from the editorial board than about a bunch of other things that seemed to me more important. It's just funny.

ROSEBERRY: Who was doing these other trials?

WILFERT: The Centers for Disease Control did one in Ivory Coast. The French ANRS, and I'm not going to be able to tell you what they stand for. It's like, the CDC did one in Burkina Faso and the Ivory Coast, and the Centers for Disease Control and the Thai government did the one in Thailand. Not pharmaceutical companies. Truly with public health interests at heart. And the Thai—Thailand has the best program in the world for prevention of mother-to-child transmission as a result of this trial, and others that they have subsequently done. And the Africans sort of said, Just a minute. We did this on purpose. We totally understood what we were doing. We knew what the options were. Nobody made us do this. This is something we had to do if we were going to get any sort of help to our mothers. That didn't matter. It was kind of scientific imperialism. It really was. But people have very strong feelings about it. So that's the way it is. But then there was another trial, equally as tempestuous in terms of the results. And it compared nevirapine, a single drug. And you could just take one pill if you're a mom and give one pill to the baby. And it compared that to AZT. The nevirapine pill that was given to mom—the trial was to give it to mothers when they went into labor, and then to give the medicine to the baby when the baby was first born. Because that period of time is when the largest proportion of babies become infected. It's exposure to mom's blood and so forth. So the AZT was given for the same time period, and nevirapine worked. It reduced transmission by fifty percent. Just one pill for the mom and one pill to the baby. And that sort of started the real feasibility of programs to prevent mother-to-child transmission in the developing world. Folks in some places were trying to give four weeks of AZT, which is what the Thai trials and the Ivory

Coast trials did. But even four weeks of AZT is logistically difficult and was expensive. It's a lot cheaper now because there are generic drugs, but it's still logistically difficult. But having done this with nevirapine, it seems like people are looking for controversial subjects. So somewhere along the line, a few years later—that was in 1999, somebody decided that they would investigate the trial which was done in Uganda at Mulago Hospital in Kampala. And they found, first of all, that the data were very solid. The data were correct. There was no irregularity in terms of recording people who were infected—kids who were infected and who weren't infected, and on and on. But there were some irregularities in some of the paperwork, so the basement of the hospital got flooded, and some rats ate some of the records. And you know, this is Africa we're talking about. And the people who had done this knew-you know, the record system isn't real good. In fact, it's almost nonexistent in most places. So they recorded all the information on a duplicate record, which they kept for study purposes. And the FDA has a way of deeming things primary source or secondary source, and the folks—this is how absurd it gets. The folks actually wrote in the real record first, wrote in the record for the study purposes second. So the primary source was not there for the ones that got flooded and eaten by rats and stuff, and it's that level of criticism of the trial, not the criticism of the data, but it has been circulating for the last seven years. And the people at Hopkins who actually did the study have been maligned. Their work in Uganda was closed down temporarily, and now somebody who has a very strong opinion about this is suing them through the Justice Department. It hasn't ended yet, and it's seven years later, and they have just been, to my way of thinking, unnecessarily traumatized and criticized. In the meantime, the world is using this. It's hard to explain, but those are some of the quirks I guess of doing highly visible science in an area that is very much in the public mind. And so it goes on. It hasn't stopped yet.

ROSEBERRY: So is there also a difficulty with kind of crossing international—of doing science internationally, I guess is what I'm trying to say?

WILFERT: Most of the scientists, or, in particular, physicians who are trained in the United States really work in the United States. And we have very high standards and are fortunate to have very high quality of care. It's very easy and tempting for folks to assume that if you know that some medicine works or you know that a vaccine works, all you've got to do is tell people, and it'll be done. And to envision transplanting a mechanism for that to happen, which is like it is here. If they went once to see what the circumstances are, it would help their knowledge base about understanding that. So lots of pronouncements are made that are well intended, but uninformed. It's hard to work in the developing world if you want to do a clinical trial, and to have the data be valid, and to have the right monitoring, and all of those kinds of things. And it takes a huge effort to set up the capacity where you're working. And there are now at least half a dozen—there are probably more—places that can do that really well, and let's hope that they continue to expand. And in the meantime, providing the services and the programs to the people who need them is not easy. They have free health care in most places. They don't have free school, but they have free health care. But the infrastructure is minimal, and what they actually get for free health care, we would all hope for more. They're getting <u>NAO</u> care. That means iron and vitamins and an examination and a blood pressure and some malarial medicine. That's probably what the standard is. Tetanus shot. I may have left off something else. And there will be two hundred women a day sitting in a clinic, and they're seen by one nurse. I mean, there's no doctor in most of these clinics. There may be a clinical officer who's not a physician but has been trained for three years, sort of like a physician's assistant. So if you envision just rolling out complicated regimes of medicines to deliver in those circumstances, first of all, if the

clinicians or the nurses—they could probably do it, but most of the countries don't let nurses prescribe medicines. There's an essential drugs list. Furthermore, they're in and out maybe twice, optimally four times during their pregnancy, but usually not. Only sixty percent of pregnant women in the developing world ever get into antenatal clinic, and only sixty percent deliver in a health care facility. So you just sort of look at those numbers and think, so how are we going to impact the incredible conditions that exist? And one pill at the time of delivery has a much greater chance of impacting the system than four weeks of medicine taken three times a day. Like it or not, it might not be as good as triple drugs, but it's better than nothing. So it's been six years, and only ten percent of the women in the world who are pregnant have access to prevention for mother-to-child transmission. It's a big problem. So that's what I do. And I'll die still doing it. It's huge.

ROSEBERRY: It sounds like it's become your passion.

WILFERT: Well, it is, because I think it's possible to reach people.

(buzzing sound in the background)

WILFERT: Excuse me. It's probably Sherri.

(sound of Dr. Wilfert walking away from microphone and then back)

WILFERT: And so when I retired from Duke, which was ten years ago, the [Elizabeth Glaser] Pediatric AIDS Foundation asked me to come to work for them, and that was before we knew about nevirapine and one dose, but it happened while I was working for the foundation. So we started programs with donations from people to deliver the services. It's incredible, actually. If they had told me when I started this that it would grow like it has, I never would have believed it. But it has. We got a fifteen million dollar grant from the [Bill and Melinda] Gates Foundation, and we got a million dollars from Boehringer Ingelheim, and some other donations. And we

started in 2000 in eight countries, and through December of 2005, we've worked in twenty countries and have provided services to over two million women.

ROSEBERRY: That's wonderful.

WILFERT: It is wonderful. It's just incredible. It's not enough. It's a drop in the proverbial bucket, but it's certainly better than nothing. And we've also taken on-we have US government funding now, CDC [Centers for Disease Control and Prevention] and USAID [United States Agency for International Development], so we've expanded the services using those funds. And we're providing care to people. I've lost track, but I think that there are more than one hundred thousand people getting care and support, and seventy-five thousand people getting antiretrovirals because of the programs that the foundation supports in Africa. It's really fun. I mean, it changes your perspectives and priorities in a major way. I mean, it's not nice. I'm grateful for everything we have, but the disparities are so huge. The United States could help a lot more than we have helped, and that's sad. I mean, it's just really sad. Bill Gates is a phenomenal person. He's recognized this, and he's happily contributing billions of dollars to try and help. More than the US government, probably. I'm not sure, but probably close. ROSEBERRY: So by help, it sounds like there needs to be some financial resources. WILFERT: Oh, there has to be, but if the people aren't healthy then they can't build their own economies. And for a long time, we looked at it the other way around. Well, we'll just give them money and set up businesses. And that's part of it, and it's a good thought. But if people aren't healthy, then you really can't change things very well. When you hear the numbers, which I can't recite, about how many school teachers and professionals die every year just because of HIV, never mind tuberculosis and malaria, it's hard to imagine a stable economy when the productive folks are dying of diseases that we know how to treat or prevent. I mean,

clean water would change the face of the earth. The life expectancy in a lot of African countries is mid forties. It's hard to imagine being born in 2006 and expecting to die by the time you're forty-five. I think until you go and see how hard people work and the problems with health, we—meaning me, too—in the beginning, I tended to look at it through US eyes. I just didn't comprehend what the differences were. Our programs require money. They're run by the people in the health-care systems. They're integrated. If we walked away tomorrow, the capacity and the institutions and the people would be there, but the money wouldn't be there. And it requires little, smaller amounts to keep programs going, but the governments don't have it to inject. So they're already understaffed. In some cases we have hired staff through the hospitals so that they have an increased number of folks. Those people would be gone immediately. There would be no money to support the logistic systems of transporting drugs to hospitals or keeping track of laboratory work. All that would go *pppfffttt*. And so even though we would know how to do it, they wouldn't have the money or the physical resources to do it. It's going to be needed for the foreseeable future. If they would stop having wars, get stable, maybe some countries would have a better shot at it. I'm sure it's overwhelming and discouraging to folks who take for granted. You know, you have good roads and good schools, free education. You have to pay for medical care, but that's just the way life is. And it's a right. The trouble is that it's not a right for most of the world.

ROSEBERRY: So has your focus predominantly been on Africa?

WILFERT: Africa and Asia. Mostly Africa, because that's where there's more disease, but we have programs in St. Petersburg, Russia; Georgia; the Dominican Republic; and six programs in India. And I've been to all those places. The only one I haven't been to is Lesotho. ROSEBERRY: How often do you travel?

WILFERT: Oh, it has been—the foundation has a rapid expansion also because there were twenty-five people when I came to work for the foundation, and now there are probably two hundred in the States and more than that. We have ten offices in countries overseas. We didn't have any in the beginning. So I travel six, sometimes eight times a year. I spend sixty, seventy percent of my time not here.

ROSEBERRY: And so you're the scientific director. What role does that—?

WILFERT: Well, I directed the organization of the PMTCT [preventing mother-to-childtransmission] programs in these various countries, so that meant I didn't have to set up the office, but I certainly had to help find the technical people to do the work. I had to educate myself and learn about how the programs run on the ground so I could help them do that. So I've had the privilege of being in hundreds of clinics all over the world to set this up. It's hard. I wouldn't try to run a clinic at Duke without seeing what it looked like and how it functioned, and the same thing is true for the developing world. There are some similarities, but they're all different. So learning about them—and we're guests, of course, of the host country. The ministry of health certainly has the power to write their own guidelines, to set up procedures, to say what's going to be done in their country, and you need to be in accord with that. You can't just say, Well, I know better. I'm coming with my money. Leave me alone; I'll do it. That doesn't work. So you need, then, to understand what the policies are and who develops them, because sometimes you can influence them politely and participate. And that's all part of having the programs incountry. So I guess for the PMTCT programs for the foundation, I'm the buck stops here, but there are a lot of people doing the work.

ROSEBERRY: So what about pediatric AIDS in the United States? Is that fairly well controlled?

WILFERT: Well, if you go to our clinic in the division of infectious diseases, what you'll see is a group of kids who are almost all getting to be teenagers. They're probably late elementary school, I suppose, up through teenage and college. There aren't little babies and kids any more, and that's a good thing. It means we have shut off, for the most part, new infections, and the kids are able to survive on their treatment. And that's true all over the United States. One of the sad things, I think, is that in the beginning of the epidemic there were estimated six to eight thousand HIV infected women a year who had babies in the United States. There are still six to eight thousand. Maybe more, actually. So we've not done real well at diminishing the infections in childbearing age women. That's the sad part. The good news is that if women get antenatal, you can come close to preventing all of the infections in their babies, and we've dramatically reduced it. I think the CDC gets less than fifty cases a year reported to them of AIDS in-what's our population? Three hundred million, four hundred million people. So that's a major accomplishment in the US, but it leaves us with a population of kids who are infected. Who require care. And because there are relatively small numbers, the same old business with advocacy in trying to get support to take care of them. A lot of them are medicine experienced. They need new medicines. The new medicines aren't necessarily developed in children. And their parents in the advocacy groups feel very strongly about maintaining the support. And the clinical trials have provided a lot of that in the United States. But the truth is that the numbers are so small that it's difficult to justify the same quantities of money in clinical trials when there are 600,000 infected kids born every year in the rest of the world. There are more children born in a single day in the rest of the world than were born in a whole year in the United States, when it was at its worst in the United States. So that doesn't make me feel—I mean, I do feel the responsibility for the kids here. That's not the problem. It is that we have so much in the way of

resources, that we owe it to all those other kids out there to share those resources. That's a hard thing. Parents feel like you're abandoning them if you diminish the work in the US, when their kids are getting good care. It's not that you're withdrawing their care. So that's one that I'm sure that there will continue to be tensions between the domestic programs and the international programs. It's destined to be for a while.

ROSEBERRY: Are there any specific cases that stand out to you or that stay in your mind? WILFERT: Well, there are lots of them. I think if there is a silver lining to HIV, it's the people. There are a lot of people whose careers and what they do for their entire life has changed. They may be infected, but they may not be, and so first of all the dedication and the work of people is pretty incredible. They have changed the medical care system in the United States in a favorable way. And a lot of people know one another who never would have crossed paths before this. And that's a good thing, both internationally and nationally. So if there is something good about this awful disease I think it is the strengths and people that are coping with it, and helping others to learn and cope with it. There's a woman who's still in Durham, who was a young woman, I think probably in her thirties, but I'm not positive. A professional woman, as was her husband. And they waited to become financially stable, and bought a house, and so forth. She actually didn't live here at the time, but her family lived here, so she came back. And during her first pregnancy her husband became ill, and was diagnosed with HIV. She was pregnant, diagnosed with HIV, and she chose to have the baby, and the baby was infected. This was before AZT. And her husband got sicker, and she got sicker, and her child was one of the first children that we enrolled in the AZT treatment trial at Duke.

ROSEBERRY: I'm sorry to interrupt. I want to be sure to get this story, so I don't want any noise to bother that.

WILFERT: So her child was one of the first to be enrolled and to get AZT, and the baby did well for a while. This woman's husband died of HIV, and she became a single mom with HIV, and got treatment for herself. And then her baby died, and then she remarried, and her husband was killed within months in a car accident. I think if I were she I'd have stuck my head in the oven or something. You know, enough already. She continues to work every day. She's just one of the strongest, most fabulous people you could ever meet. And most people don't know word one about losing two husbands and a baby and being HIV infected. And I never would have known this woman. No way. So there are a lot of people like that. If I told you what she did, I'm afraid I'd give away who it is.

ROSEBERRY: Well, who are some other people that are in this fight with you?

WILFERT: Oh, there's thousands, fortunately. I mean, John Bartlett, who works at Duke, does this in the adult infectious disease group. And he's opened a program in Tanzania. So they work in Kilimanjaro, which is in Moshi, Northern Tanzania. So he's doing some research there, and there are a lot of infectious disease students and fellows and faculty who go back and forth. Colleen Cunningham from Peds does. And there will be more, fortunately. And there are a lot of people, twenty-four thousand people in Toronto at the HIV conference, and they're all workers one way or another. That's a sample. We'll have a meeting in October of 250 or so people who work with us in Africa, in Nairobi, in Tanzania. So there are lots and lots of people working.

ROSEBERRY: So what should we know, what should we as Westerners know about this struggle or about the developing world?

WILFERT: Well, I think it's important that people try not to be judgmental. People may be poor and work very hard, and there's a bit of a tendency to be judgmental and assume that if

people are poor, they must be lazy or not working or something. And it's just not the case. So if folks could just not be judgmental, and if they could open their eyes to the living circumstances, they'd probably realize that there's a lot that could be done to help. And we vote for our governments and their policies, and we can stop them, or our representatives can stop providing resources if the constituency says so. And that would be terrible. But to be encouraging and pushing people on to do more would be a good thing to do in the Western world. People could think about it. This is so much a global community, and it will be ever more so. People just don't—they have no idea. If they just thought about it for a millisecond, they would. Oh, when we invaded Afghanistan we did in Kenya's tea industry because Afghanistan is the largest purchaser of tea from eastern Kenya. So they went through some bad years. Now it's just the consequences of taking on something, and then what happens downstream, which probably doesn't occur to most people. The market ladies in Côte d'Ivoire are flying to the Middle East to sell their goods. I don't know what kind of goods. I do know that the airfare isn't cheap, but Côte d'Ivoire is sort of unstable to say the least, and there's a lot of money in the Middle East. So it's become more remunerative for people who can afford an airplane ticket to go and sell in the Middle East, in Dubai or someplace, to sell their goods. Now, Dubai probably doesn't grow a lot of vegetables. That's my guess, because it's mostly sand. Who knows that people from West Africa are flying to the Middle East? Nobody. Do you know that China is probably one of the biggest supporters of things like hydroelectric power in Africa? They build the plants. Japan builds roads. So if people think that we're just so secure and independent and financially stable without what will ultimately be huge needs from the rest of the world, they're going to be sorry. They'll be surprised, and not pleasantly, I don't think. It's just mind-boggling. And people abroad have very strong opinions about the United States, and they're not all good. They think

we're selfish, and they're probably right. And they just don't understand why we attack Iraq. It doesn't mean they like Saddam Hussein. It just means, so isn't there another way to deal with this? When they get to know you, they're very outspoken, which is kind of nice. Because when they get to know you, they know that you won't take it personally, and it's just a comment. It's an eye opener. It's kind of healthy. I have friends in Zimbabwe who asked me if Mr. [George W.] Bush could read. And I thought that was a good question. But their view on the TV is that he probably can't read.

#### **ROSEBERRY:** Why is that?

WILFERT: Because he doesn't speak well, and he fumbles around. I have no idea. I just think it's sad if the perception of the world out there of the man who leads the country has them ask a question like that. That's not a happy thing for me. Without passing judgment, I can only say that's the image that he's created. I didn't do that. So what else do you want to know? ROSEBERRY: Well, what questions have I missed maybe along the way?

WILFERT: Well, I think since this probably relates to a lot of other things that have changed and are happening at Duke I think I've carefully avoided because (a) I don't like, and (b) I'm no longer involved. The changes in delivery of medical care, which are not easy to accept if you're old enough to have been in the system before. Now there are—you're supposed to see so many patients in a short time. There are some patients who are eligible and some patients who aren't, and there's somebody on a phone from someplace calling and telling you that you can't do that for this patient. It won't be reimbursed, and that's not what medicine is really about. Medicine's about taking care of people. So I think that's dramatically impacted the lives of all physicians. I think it's easier for younger physicians who grew up in the system and that's the way it is. They didn't know it another way, but it's exceedingly aggravating. I mean, there's nothing like having somebody who's never seen a patient in their lives call and tell you that, Well, we're sorry, we only allow two days in the intensive care unit for that diagnosis. So then you figure out how to make the diagnosis one that can be covered for more than two days. Because the patient's still on the respirator. What are you going to do? That kind of push-pull tension didn't exist in the old days. You made a decision, you did the very best you could to take care of patients, and it was respected and reimbursed. Not any more. I'm sure it has to influence everything about the medical center, and it certainly influenced us. There are a lot of—sort of—they've come to be funny stories, but they were annoying stories. As these changes took place, we were asked to document our consults and our time, because the people who reimbursed were just sure that we were probably being reimbursed for time we didn't spend. Okay, so we got very compulsive about turning in our consult sheets, and contacting people to be sure it was reported, and it took lots of time. And they learned that in fact, we were spending a whole lot more time than we were billing for in the beginning, and it got to be more expensive to take care of patients. But that's the way the system is currently functioning. It's succeeding. I mean, the rules about accessing information are meant to protect people, but they also hinder care. It's probably-I don't know HIPAA [Health Insurance Portability and Accountability Act], because I escaped before it came into being, but you can't access information about a patient if you're not the provider. And in the meantime, somebody's asking you about the patient. So, speaking for myself, if I lived under that system, I'd probably break the rules all the time in order to provide better care for patients. And I'd be surprised if that doesn't happen regularly. It's not about giving away secrets or privacy. It's about sharing medical information. I'm not-the mother who delivers, if she delivers in our OB unit, I'm not her doctor. And the information from her chart is not on the baby's chart. But I regard that information as important to the baby that I'm

taking care of. What if she has syphilis? Which she could have given to the baby. It ought to be an automatic. The system ought to work so that those kinds of things are relevant, but I don't believe that it is yet. And I think if you're in the hospital, you can walk down the hall and find the obstetrician and read the mother's chart, but if you want to access it electronically when you're trying—you can't do that. You're not supposed to do that. It's bad for medical care, I think. It's not enhancing communication. Everybody else gets to live with it. I don't have to. ROSEBERRY: Well, if you don't mind my asking, what has it been like working with Dr. Katz, working with someone that you're married to?

WILFERT: Well, we share the same interests, so it's a pleasure. If we didn't share the same interests, I'm sure I wouldn't be traveling sixty percent of my time, because any person other than Dr. Katz would have gotten fed up with it a long time ago. And as far as Duke went, he did not have administrative or financial responsibility for me. The dean did, so I was in the department, but the person who was responsible for me was not the chairman. And as far as I know, there were never any issues about that. There were an enormous number of people who never knew we were married. Not faculty, but others, just because our names are different. One of our medical students once was interviewing for a position in pediatrics. We love to tell this story. I don't know when it was. This was probably in the eighties. And he went to Boston University, and the chairman of pediatrics was a friend of ours, and so he asked him if he knew Dr. Wilfert and Dr. Katz. And the student said yes, and then using very bad judgment he said, "And I think there's something going on between the two of them." Our friend said, "So what do you mean?" and the student said, "I think they're having an affair." And our friend said, "Well, I hope so. They've been married for twenty years." It's just so funny. We haven't tried to hide it or anything, it just seems like that's really funny that a medical student could be here

four years and not have figured that out. I don't know if he got a position or not. I don't know if he wanted to. I don't know what he chose to do. Anyway, so as far as I know I don't believe that there were difficulties within the department or the medical center because I was married to him, and clearly the things that would cause trouble, promotions and money, were not Sam's responsibility.

ROSEBERRY: Is that typical for the division to report to the dean?

WILFERT: No, it's just that I think when we decided to get married I think that Sam went to the dean and said, there will be this issue, and we need to be sure that it's appropriately managed.

And so the suggestion was that my stuff would be in the dean's office and that would do it.

**ROSEBERRY:** Was that Dean Davison?

WILFERT: No, it was Bill Anlyan.

ROSEBERRY: Bill Anlyan. Okay. Well, again, if I've missed anything.

WILFERT: I fear I can talk forever, but I don't want to.

ROSEBERRY: Well, that's an oral historian's dream, is someone who can talk forever. I really appreciate it. This has been a delightful morning, so thank you.

WILFERT: Well, it's been easy, so thank you.

ROSEBERRY: Good. Thank you very much.

(end of interview)