

DAN ROYLES: [00:00:00] There we go. This is Dan Royles interviewing Dr. Victoria Cargill at the University of Pennsylvania on May 15, 2013 for the African American AIDS Activism Oral History project. Just to get started, can you tell me a little bit about your early life?

VICTORIA CARGILL: My early life, you mean my childhood?

DAN ROYLES: Yeah.

VICTORIA CARGILL: I grew up as an only child. My dad was a licensed practical nurse but he worked on the New York City Health and Hospitals Ambulance Service, which gave him quite a bit of exposure. My mom was a former nursing student who married my dad and went into business. So I had a great exposure to medicine at a young age. I grew up on a farm and started helping tend to the critters that we had and decided at the age of nine that I wanted to be a physician. That's how I got started in all this.

DAN ROYLES: Where was the farm?

VICTORIA CARGILL: The farm was in upstate New York, outside of Saratoga Springs.

DAN ROYLES: Can you tell me a little bit about your educational history?

VICTORIA CARGILL: Sure. I was an early learner. My mother, before it was popular, home schooled me before I went to preschool. So I went to kindergarten knowing how to read and was quite bored, and so went on to a parochial elementary school and skipped a number of grades with a group of kids who became friends. By the time I'd entered sixth grade I think I was nine, so I graduated from high school when I was sixteen and then went on to college, graduated from college at twenty. I was very fortunate to go to Mount Holyoke College and to graduate with high honors and to have one of the very old alumni

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classes, the class of 1906, pay for my first year of medical school because of my GPA. And then from there I went to Boston University School of Medicine and then went to Harvard for my residency.

DAN ROYLES: You did a fellowship at—

VICTORIA CARGILL: Yes, I did a fellowship here at Penn. I was here, the Andrew W. Mellon Fellow at the University of Pennsylvania in epidemiology. And from there I was recruited to Case Western Reserve, where I really continued my work in epidemics and started an AIDS education organization. [00:02:00] Finished up here, went to Case, and then from Case was recruited to the National Institutes of Health, where I am now.

DAN ROYLES: What year did you go to Case Western?

VICTORIA CARGILL: I went there from 1984, and I left in 1998.

DAN ROYLES: What was it like?

VICTORIA CARGILL: It was an interesting experience being at Case Western. I came straight out of fellowship. I had always been an East Coast person and so I had several transitions. I was going to the Midwest, which I'd never lived in. It was far from home, which was an issue for me. I had decided to do internal medicine and some research, I was looking at colon cancer research. And just when I arrived at Case Western, Ohio ranked twenty-sixth in the country in AIDS cases. But in Cleveland they were having a problem with more and more AIDS cases, and so the year I was there, that first year Ohio went from twenty-sixth to thirteenth in rank. And I was seeing patients in an outpatient setting but was asked would I be willing to help the Department of Health look at their epidemiology statistics. That

literally was the last time I saw basic internal medicine by itself—I always saw it with HIV infection. It's also interesting because Case Western and Cleveland were much more of a racially segregated institution than I was aware of at the time. There had been tensions between African American physicians and white physicians that has subsequently improved. But by the time I left, I left as a full professor of medicine, but I was only the second Black woman in the history of that institution to achieve that rank.

DAN ROYLES: Did you feel that tension manifest in your professional life?

VICTORIA CARGILL: It manifested in many different ways in my professional life. I was the director of the ambulatory care center and when I arrived the patients were scheduled for appointments as one block. In other words, whether you were going to be seen at one and I had a one thirty, it didn't matter, we both got a one o'clock appointment. So as you can imagine, people didn't want to come to clinic, and when they did, and often sat there for three, four, five hours. I found this completely unacceptable. I also found it unacceptable to have a parallel system of care. If you had private insurance you went to the private practice, if you were [00:04:00] in this resident clinic you had many medical problems and a long wait. So I basically changed the system. And when I did that I got a lot of push back, a lot of push back.

DAN ROYLES: So, it was a parallel system for publicly insured versus privately insured?

VICTORIA CARGILL: Exactly.

DAN ROYLES: When did you first become aware of AIDS, or what would become known as AIDS? I assume it was before—

VICTORIA CARGILL: Oh, it was long before. I was a resident finishing up my residency at the Brigham [and Women's Hospital] in Boston, and I had started working at Brookside Park Family Life Center as an attending and as an independent physician. I should say that the reason I did that was usually you finish your residency—especially if you're a Harvard-trained person—you go on to a fellowship. I was tired of being told what to do. I didn't have any problems telling people that I needed a break. And I wanted to give back, on top of needing a break. When you're a resident at a teaching hospital most of the patients that you really learn from aren't just the patients who the private attending manages, telling you what to order and how to do this or that: it's the publicly insured patients that you really have to manage medically and with their socioeconomic issues often have to go to the mat for. You have an attending who's quite savvy and helps you every step of the way, but you're really becoming the doctor in charge because when they leave, they come into your clinic practice. And I felt a great deal of responsibility to give back to those patients because they taught me a lot. You know, you're up at two, three, four, all night with them, and sometimes you decide to do things and the attending comes in the morning and says, "No, no, no. We're not going to do it quite that way." But I felt I needed to learn to manage medicine in the context of social determinants of health. So, I went to Brookside Park Family Life Center and I worked there as a clinic doc, but as a clinic doc the compensation was relatively limited (I had many student loans to repay), and I also wanted to see patients from a number of different perspectives. There, the practice was almost 60 percent immigrant, a lot undocumented. I learned very quickly medical Spanish. But I wanted to do more and so I knew that the Fenway Center needed part-time docs and so I worked there part-time. [00:06:00] It's funny: Ken Mayer says that the Fenway still feels

that they'll claim me even if I was only part-time. I happily will accept that claim!

I was working at Fenway as one of the docs when I saw my first case of HIV infection long before we knew what it was. Back in the day, it was called it GRID (Gay Related Immune Disorder). I'll always remember that young construction worker who came in on a Saturday, of course, at eleven o'clock, of course, because the clinic closed at twelve. And it was the look in his eyes that I knew there was something really wrong. Patients who know they have something bad, a lot of times know it even if they don't say it. And he kept saying to me, "There's something wrong. My partner said he saw these things on my back and I should get them checked." And when he pulled up his shirt there were these gigantic purple lesions staring at me in the face and I thought, Oh my God, I just read the *New England Journal* report out of San Francisco and I'm looking at this. And I'm trying to keep my face intact, but I'm saying to him, "I think we need to do some blood work. I think we need to get your partner in here. I think we're going to need to have a talk." And he was just falling apart, and that was the beginning.

To me, I always think it was like someone taking a rock and throwing it through a plate glass. Every stereotype I had went out the window. Every preconceived notion I had went out the window. And any sense that I had of sitting on the sidelines and this being an interesting disease that we could speculate about—was it CMV or was it a different manifestation of this, all of that was gone. Here was a healthy strapping twenty-eight-year-old muscular construction worker, still had his boots on from the site, weeping uncontrollably because he knew what was in store for him. I don't know, I think you can't look at that kind of pain and that kind of disruption to someone's life and not be

compelled—at least I felt—to step in and do something. And he was dead in December and I met him Fourth of July weekend. That was my introduction to HIV and it was the biggest smack in the face that I've had clinically in my lifetime.

DAN ROYLES: [00:08:00] Do you remember what year that was?

VICTORIA CARGILL: Yep, that was 1984.

DAN ROYLES: You said it erased or destroyed some stereotypes or preconceived notions—

VICTORIA CARGILL: Actually, I take that back. I'm wrong, because that was before I went to Penn, so that was 1982. I went to Penn later on that year. That's why I remember when he died because I had told them I would be leaving and near the end he said to me, "I won't be alive. You won't leave me behind, I'll leave you behind."

DAN ROYLES: What were some those preconceived notions from before that experience?

VICTORIA CARGILL: You know, I grew up on a farm. I grew up in a very, I'd like to say, progressive family. My father's a jazz musician on the side so we had all kinds of people floating in and out, and they were very open about things. But in other ways, just through my life experience, I just wasn't exposed to a lot. I didn't know very many people who were gay at that time. It's ironic because now a lot of the friends that I was the closest with in high school have come out, so maybe I did and just didn't know. But I had this sort of mental stereotype in my head of what a gay person or a gay male would be and this man blew them all out. He was a construction worker, he was fearless, and yet this little thing that we couldn't see under a microscope without high power had just terrorized him. So that was one. The second was what gay relationships were like. I think it's easy, especially

in a parochial education, you hear stereotypical comments about, whether it be promiscuity or lack of commitment or somehow heterosexuals are different, and what I saw early on in the epidemic blew that out of the window. Here were people facing unbelievable illness and complications and yet not only their partners, but their whole community would come and help make food and change sheets and help take care of them. It changed my perspective on a lot of things. And it made me not only a changed person, but a vocal—as some of my patients will tell you probably, rabid—changed person.

DAN ROYLES: And when did you become aware of racial [00:10:00] disparity in the epidemic, that this was going to be a particular problem for people of color?

VICTORIA CARGILL: I don't think I appreciated the racial disparity of the epidemic until I left Philadelphia because when I came to Penn, I'd been at Penn all of four or five months when there was a code called up on the sixth floor of the building. And as we were running up the stairs we talked to each other, like, "Who's on six that could code?" "I don't know." "Well, who do you think it could be?" "If I said I don't know, I don't know." "Do you think it could be that guy in the back that had PCP?" And literally, you could almost hear everybody go (imitates slamming on vehicle brakes) and start walking. It was like, Wait a minute now, how are we going to do this? But these were still white gay males and my biggest comeuppance while in my training here was running up the stairs to see a young man who was getting into trouble with his breathing and the nurse had paged us and I was the fellow on the service. And I saw all the isolation gear—people forget how much we had to suit up with all that stuff—and went running in the room only to realize I was confronted with the face of someone I knew very well from my church. Of course, as you can imagine, it's a

complete unmasking because it's not whether or not there are whispers or suspicions that someone may be gay or involved in a relationship, but it's out there and it's out there when someone's at their most vulnerable. And I told Frank that wasn't a concern. But still, there it was still mainly a white gay male epidemic.

When I went to Ohio, that is when I really saw the disproportionate impact in racial and ethnic populations. I saw young women coming in. The women I took care of were predominately African American. There were a few Caucasian, but predominately African American. The children were almost uniformly African American unless there was a Caucasian woman with an African American partner. The men that I saw were still predominately men who had sex with men. And initially it seemed to be evenly split between Caucasian and African American, but then it began to shift more heavily.

[00:12:00] So it was really during my time in Ohio that I began to see that, which is why I started SAMM [Stopping AIDS is My Mission] because I thought these kids are out here engaged in all this behavior. We already knew the average age of sexual debut for adolescents of color and we already knew the STI rates. They were always higher in African American teenagers. So it's really not rocket science to figure out that if HIV is transmitted sexually and these kids have early sexual debut, and they have higher rates of STIs, it's just a matter of time. And so that led to the creation of trying to find ways to get these messages to them that they could accept.

DAN ROYLES: What does it mean when somebody codes?

VICTORIA CARGILL: When someone codes it means that they have a cardiopulmonary arrest. The nurses will often call if someone's blood pressure's falling or if they find

someone pulseless and breathless. In fact, there was a horrible joke that used to circulate when I was in training as a fellow, not just here, it was widespread: "How do you code an AIDS patient?" And it was always the foot tapping (taps foot on floor) and the (makes puffing sounds). Of course, being a reflection of the fact that nobody really wanted to get close and pump or do mouth-to-mouth because of the fear of transmission.

DAN ROYLES: So it was that you'd have to go and do CPR on the patient, okay.

VICTORIA CARGILL: Exactly. And that's why everybody kind of slowed down, and I would say half the people in that hallway turned around and went back downstairs. The rest of us kept going.

DAN ROYLES: What church did you attend when you were a fellow here?

VICTORIA CARGILL: I was at St. Mark's Episcopal Church. I'm an Episcopalian.

DAN ROYLES: On Thirteenth? Where ACT UP meets, still.

VICTORIA CARGILL: Yeah, really? Yeah.

DAN ROYLES: When did you start SAMM?

VICTORIA CARGILL: I started SAMM in 1988. It came about because I was asked by a colleague at the health department to go to a school and give them a talk on HIV, and I said I would. To put it in context, remember at that point talking about sex at all schools was difficult, let alone talking about sexually transmitted infections. [00:14:00] Then when you add to the mix same-sex contact, you're really out the door. So this school in a particularly poor neighborhood in Cleveland had said I could speak, but when I went there the teachers

were the most inappropriate. I was prepared for the kids to give me a hard time, but it was really the teachers. I set my little slide projector—back in the days when we actually didn't have PowerPoint, you used a carousel. I told the kids what I did and then when I started to show them some of the statistics from the Centers for Disease Control about who was getting infected, I can remember a Black male teacher interrupting me and saying, "Nobody wants to hear this because the only people who get it are punks," i.e. code for gay people. I said, "I beg to differ with you because I have people in my practice who are not punks because they are women and they got it from their male partners." "Well, them people have their door swinging both ways." He was so inappropriate I finally asked him to leave. Then another teacher said something and one of the kids said, "Why don't you be quiet so we can hear? We're trying to learn." One of the young ladies raised her hand and said, "My mother started talking to me about this and she said 'I care what you do, but I care more that I have the chance to talk to you, and the only way I'm going to talk to you is if you're alive.'" So, her mother had gotten her a keychain where you could slot in two condoms. The room erupted between catcalls, yells, somebody calling her a slut. I had to practically get a chair like a lion tamer and say, "Stop this. At least she's smart. She's going to protect herself. What do you call you? You guys act like you're not out here having sex. I know what you're doing because I see the gonorrhea and syphilis rates by ZIP code and this ZIP code is lousy with it." Well everybody then got pretty quiet. "Well, can you tell our name?" "No, I can't tell your name. But I would like you to be quiet so I can finish this." At the end the principal finally came along with one of the teachers and said, "You know, the study hall is over, if you're using the library you really have to go. But you can go out there and talk." So the kids say, "Can we follow you out to talk to you?" I sat on the hood of my car surrounded by about

fourteen African American adolescents asking questions, and then I happened to look over and diagonally across the street from me is a crack dealer selling crack. [00:16:00] And I thought, Now this is the height of—unmitigated gall—just downright galling. I'm sitting here trying to help these kids stay alive, but the drug man's out there and no one's giving him a hard time. So I said, forget it. When I went back to the office I called Len Collins at the health department and said to him, "This has been my experience and I'm really sick of it and we have to do something. I don't know what it is, but I'm going to think about it. All I know is I need your help because you run a program called Just Chillin', which is helping kids to get themselves together around drug risk, drug pressure, and drug paraphernalia being purveyed to them. I want to do something similar with HIV. Will you help me?" He said yes. He is now the Executive Director of Cleveland Treatment Center.

And I went home and—whatever your religious or moral views are—I can honestly say I spent two days praying about this, and thinking about it, and saying, What can I do? And what came to me was, you have to give the kids a mission. Give them something they can get on board for. And there came SAMM: Stopping AIDS is my Mission. We printed pledge cards. There was a ten-point pledge, which had to do with spreading the word, not being judgmental, being open to talk with others, how I'll keep myself safe, I'll talk to my church, I'll talk to my parents, all these things and then at the end you sign your name. Then I thought, Well that's not good enough, because kids learn best from each other. So I came up with a peer education program. Kids—educate them and let them educate each other. But how are you going to educate the peers? Because if the peers are getting pressure from their friends that this is not important, how would I do this? I came up with the idea, all these kids like to come out to a dance and hang. And that would probably be better because

Cleveland, like many cities, still has a fairly high dropout rate for their kids. So some of the kids we talked to in high school, but the people they're dealing with may not be in high school, they may have dropped out, but they're still at risk. So if you're only going to deal with this population, but this population may be bigger and even riskier, you have to get the word out to both. What's a common bridge then? A dance. Everybody comes [00:18:00] to those. So we got permission at a high school in the Hough, the site of the old riots, to be able to have a dance. We put out flyers in the high school, we told the kids they could bring their friends, whatever, and we found a DJ. But what the kids didn't know—but what we knew—is I co-opted that DJ and so anybody who DJed for us had to know the basic AIDS facts. Because the kids wouldn't listen to us, but they would probably go to the DJ. And that's exactly what they did. So that while he's DJing they'd come up to him and say, "Man, you know, they're here for this AIDS thing but we don't think it's any big deal." And he'd be able to tell them, It is a big deal, it's important. Do you know this? Do you know that? In the meantime, there were five of us, and I co-opted five friends, two of them were living with HIV infection, and we all were a lot younger in those days, so we could pull it off. We would wear painter's caps that had "SAMM" on it, t-shirts—always, of course, our painter's caps backwards—and dungarees and circulated among the kids. So that way when they're like, Oh man, are you one of the chaperones? You don't look like that. Well what's this AIDS thing? And that is literally how it started.

The first dance we had, we opened up, we thought we'd have twenty kids. After eighty-four kids showed we locked the door because that was more than the ratio I was comfortable with. You know, one chaperone for every so-many kids, and I wanted it to be one to fifteen. With five people and eighty-four you're already out past that. It was not only a hit, but I was

struck by who came. Kids came bringing babies and baby strollers. They brought their friends. There were kids clearly doing gang signals, so we had to have the guys watch them. But the point was they came, they took their free t-shirt, they took their painter's cap, and if you want to take that then you've got to take a brochure. And I'll never forget that night because at the end when they left, one of the kids came back and said, "That girl thinks she can fly out there." Oh my god, this girl had done PCP so I was sprinting down the Hough chasing a teenager who thinks that she can fly because she's going to get ready to jump off this ledge thing. I had to call twenty other ones who cut through—this is at 11 o'clock at night, [00:20:00] I don't know this neighborhood, I am afraid of it to be perfectly honest. But we got her, wrestled her to the ground, called the police, got her in the hospital. But that was the beginning.

And that was our start, with eighty-four kids. And from that, SAMM grew to over a hundred thousand kids. We were at one point a demonstration project in five cities funded by the Ohio Department of Health. We had a peer education program that was conducted in waves, so we'd recruit twenty kids and then get them educated and they would go out and they would do presentations along with me in schools. They would do presentations at rec centers. It got to the point that before I left we actually raised enough money to send them out to Los Angeles for the Youth Theater Project, so that they could learn to do youth theater telling their own stories to educate others through theater instead of just stories. And I remember that because when they went out I was a nervous wreck. I'd never sent a group of kids out of state, let alone on an aircraft before. I knew my own liability. I was worried about them. I was by that point a parent, I had two children. And I remember watching the tracker for their flight as they went across and there were storms so they

were grounded in Arizona but I didn't know. When the tracking stopped, and I was like, What happened? I must have called United so many times they probably wished that I would go away. They finally said, "Ma'am, they're grounded in Arizona." I then kept leaving messages the whole time: "They have to call me, they have to call me." The coordinator called and said, "We're fine. The kids thought it was a hoot to be stopped in Arizona." It's like, "I've turned white by now. What is wrong with you?" She said, "We're fine. We're fine. We'll let you know how things go." And my last comment to her was, "Have a good time. I expect them to behave. Don't come back because you're in LA all tattooed up and pierced." They sent me a FedEx package before they left. It was a picture—it's still in my office—of all the kids. They had gotten water tattoos, Shannon had gotten them these fake piercings, and sent it to me saying, "Well we couldn't follow all your advice, but it was a good conference." I almost had a stroke until they let me know it was just fake. (laughs)

[00:22:00] And I am happy to say they are still around. I turned them over to an AIDS service organization and when I went back about five years ago, the first peer I educated unfortunately died of AIDS, but the second peer I educated eventually became the executive director. Now it's being run by another executive director, but they're still going strong.

DAN ROYLES: What were the five cities that they did the demo project in?

VICTORIA CARGILL: They were five cities in Ohio. I'm trying to remember. I know it was Columbus, Cincinnati, Akron, Cleveland, and Canton.

DAN ROYLES: So when you left SAMM, was that when you went to—

VICTORIA CARGILL: I came to the NIH. When I left SAMM I knew I was moving to the NIH, and I had to do a couple things. I was doing research with HIV risk reduction in adolescents,

I was doing research with Jeff Kelly and HIV risk reduction with women of color in public housing, and when I accepted the position at the NIH I had to let SAMM go. And so that was when I made the transition.

DAN ROYLES: Those things that you said, you were going to do at NIH? Or you were doing at Case Western?

VICTORIA CARGILL: I was doing it at Case Western. And so when I came to NIH I knew I'd be looking at gaps in the portfolio, looking at policy. When you move to the NIH you can no longer maintain your funding connections, so I had to let that go.

DAN ROYLES: So when you were doing, say, prevention work for women of color in public housing, what is that?

VICTORIA CARGILL: It was a great project. It was, again, a research project that Jeff Kelly was the principal investigator. He wanted to do it in five cities, Cleveland, Ohio was one. And what his whole concept was, was a bit like peer education, but also empowering and I think Jeff was really on to something when he said, We have to stop giving people messages that you can't do this and you can't do that. Instead, what you can do and show them how they can do it. Because a lot of HIV has nothing to do with sexual behavior per se, it has to do with [00:24:00] what you think of yourself, what's in your environment. So in that particular study, which Jeff was successful in funding and we published a number of articles from, had to do with trying to help women in public housing talk to each other about risk reduction and also to then convert that talk into action in their own lives. We had to be very strategic about where we picked, because there was some data suggesting in very tall public housing, like high rises, information didn't spread well vertically. You

needed something that's fairly low and spread wide and that's what we did. We picked two control developments and two intervention developments, and we brought the women in for four sessions. It's sometimes referred to in the literature as POL, popular opinion leader. We brought the women in for four sessions. The first session was the AIDS basics, the second was around sexually transmitted infections, the third was around knowing their triggers, which was one of their favorite sessions because they got to have candles and incense. We talked about when you've had a drink or when you're in that mood, and how you can still be safe. And they also had to practice how to place condoms. And then the last session was really not only just to tie it together, but to recognize them. They got a certificate of completion. For some of these women that was their first certificate of completing anything because they hadn't finished high school. That's why they were in public housing, they had children, with limited income or only public assistance and had to have a place to live. And they could then go on and become part of the next wave in terms of recruiting people. It was very, very popular but it was hard to get into some of these developments. I can remember one of the developments I went out there the day before I went into labor with my second child, and the woman who was the—as Meshell Ndegeocello would call them—a project aristocrat, Miss Freddy, said, “Well I don't know about this. Why are you coming out here doing a study on these women?” And she said, “Come back and talk to me.” And I can remember saying to Miss Freddy, “Look at me. I'm about to have this baby any minute.” She said, “You just come back to me and we'll see.” And I think it was her way of trying to determine how committed was I to this project. So sure enough, you know, Cleveland in a blinding snowstorm, [00:26:00] my son was all of about two weeks old and I bundled him up, I put him in my jeep and I drove out there and

went to find her. And she looked at me and said, "You damn fool, bringing this baby out of this weather. Come in here and we'll talk." And once I got her blessing that was it.

We learned a lot from those projects. These women were excellent at teaching each other. We called a lot of them to create a council of their own. They called themselves Sisters United, this one development. And they would plan events for the community, everything from a Valentine's Day education, "Be Safe with Your Lover," and the housing project manager who had initially given us a hard time, he dressed up as Condom Man, which we never expected. We basically told them, You tell us the ideas, we'll be your staff. But you also can tell us what are the other things you want to learn about. Because Jeff was very clear, if we're going to do this, we're also going to give something back. So women told us, We want to hear about jobs, we want to have someone from Rape Crisis, we want to hear about abuse. And so we would also act as the staff to go and make these things happen. What we didn't expect was how widespread this would have a ripple effect. In one development, I pulled in and we were met by the men, not the women. The men were not happy with us and made it very clear because one man showed up with a tire iron, so I don't think he was there to have a conversation with me. Because he felt like we were transforming these women into people they didn't know. And, "Why is she always asking where I've been?" And, "Why do I have to use a condom?" We had to say, Because we're teaching them about this, and eventually try to get them to understand that if she's being safe, it's safer for you as well. But that was one. The second one was one of the developments the administration was not that fond of us being there. They sort of tolerated us and at times they could be a bit difficult. But in the spring near the end of the project one of the administrators came out and found me during a session. She said, "I have to tell you I

can't believe the numbers I'm seeing." Because in public housing [00:28:00] you're allowed so much space for your children and for you. If you have an unintended pregnancy you've got to be moved, which creates, as you can imagine, all kinds of shuffling around. It makes it difficult. She said, "Do you realize that since you guys have been here in that last two years we've not had one single unintended pregnancy we didn't have to plan for?" And the enormity of that did not sink in until I was driving home and I thought, No unintended pregnancy means these women have not only taken our suggestions to heart, they've told others. We had to get 80 percent of the development to have the power to analyze the study and I think in our case we had 85 percent. We were very fortunate. So that was the second thing. But the third thing, which I really wasn't prepared for, is we gave these women little identity cards because in that particular development they felt they didn't want just anybody just drifting through. And so we said, Tell you what, we'll make up a little card and you have that and you know who's supposed to be here and you know you're in our session. We didn't think much of it. But that particular development had a problem with drug dealers coming in from another neighborhood trying to sell to their kids. And they were a fairly disrespectful bunch, as you can imagine. But this development is built so that you could come in on the bottom floor, but they had little mini balconies above, and they sat side by side by side, so I could yell to your balcony and you could yell to the next balcony. Or we could go inside and call each other, and then come out together on our respective balconies. So one woman came out one night and she saw this drug dealer and I think she said, "Hey, you don't belong here. You need to get out of our neighborhood." He blew her off. So she said, "I'm going to tell you to get out of this neighborhood or we're going to have something for you." He blew her off again. She went inside and called the

neighbors. So the next neighbor went out, did the same thing, he blew her off.

Unfortunately for him, he chose to walk along that side. Now there are many ways you can give people a message you don't want them, but an old tried and true one is the boiling hot water dumped on you from a balcony trick. And you know, when you have a bunch of women who've had to put their differences aside to talk about HIV and educate their kids, and once they understood the link [00:30:00] between these drug dealers and drugs and their kids and HIV risk, they called each other and they got out on their porches and they threw so much boiling hot water down on these drug users, they never came back. And I consider that one of our biggest victories. That we actually empowered these women to be able to say, Not in my community. Because you can imagine, as just one, they'd be terrified because a person would come back. With that group I think you're going to be a little bit too busy taking care of your burnt skin to be able to come back to a whole bunch of these women—angry women. And they were quite proud of that and they should have been.

DAN ROYLES: So what prompted the move to NIH?

VICTORIA CARGILL: There were a number of factors I think that were happening both professionally and personally. Professionally, I was struggling with being in an institution where I didn't fit. I was not a board-certified, and still am not a board-certified, infectious disease specialist, and so there was a sense that I had that I was considered less than because I was not ID trained and boarded. It didn't matter that HIV infection, from my perspective as an internist, because it affects so many organ systems and because it affects the person's whole being, is really an internal medicine/primary care, i.e. every organ system, disease. This initially emerged under the purview of the infectious disease

specialist. And so the fact that I could spell *Pseudallescheria boydii* or mycobacterium avium complex didn't matter. What mattered was that I wasn't part of the card-carrying group. I was also then caught on the other side in a division of general internal medicine where the chief at that time did not feel that HIV was important, and in fact felt that I was sort of outside the reach of the division. So you have one division that doesn't really necessarily think that you're all that, except when you're on television a lot because you talk about HIV, and then you have the other side that thinks that you're really not in general internal medicine because you don't really see general internal medicine patients, and your research isn't general internal medicine. So it made for a lot of discomfiture. The second was [00:32:00] that I could see after having been promoted, the struggle that I went through to do that, and to have people say to me that the only reason that my work was prominent was because HIV was just the disease of the month, was very hurtful. This is after three or four NPR interviews, a number of public service announcements—I'm sure you've seen some of this on the web. It was just really a lot to swallow, especially given the reach we'd had into the community and the fact that I created an organization, which became like a bridge between the community to the institution. It completely devalued my sense of commitment—even obligation—to do something to decrease the transmission and impact of HIV infection within communities of people who looked like me. It really deeply wounded me.

Personally, there were reasons. My father had died in Cleveland. I had brought him to Cleveland because he was struggling with this metastatic—and unfortunately fatal—colon cancer. I had two children at the time who were both diagnosed with learning differences, and my older child was diagnosed with an autism spectrum disorder. So I really began to

see SAMM and the work that I did that I loved so much becoming like the tail that was wagging the dog. I had to figure how I could still do this, but how can I be present for my children? I had been very fortunate that I had not missed anything important in their lives, but at what expense? I barely slept three or four hours a night. There were times when I would come home and I'd literally come up our driveway and go right back out the other side because my pager had gone off and yet one more patient was dying. I had made a pledge to all my patients: when you died, I did my best to be at your bedside, unless there was something that had come up where you died at home. There were many nights I would get up at two, three o'clock in the morning, kiss the children and then call my mother and say, "I'm going to be leaving. Can you come over?" And head down to the university hospital to sit by somebody's bedside until they passed or to sit with the family because they had passed and I had just gotten back into town. So those were a lot of the reasons why I left.

I hadn't been looking for this, but my phone rang and I had been called by the then-Director of the Office of AIDS Research, Dr. Bill Paul. He had called a couple of times earlier, but every time he called I had [00:34:00] managed to have my assistant or my secretary take the call and say, "She's in the field. She's not available right now," because I was very undecided. This particular day everybody in the office was gone. I'd sent everyone out to do either a health fair at Hough, or with the other group doing peer theater, and those teens were down at the city health department at the recreation sites. So literally everybody was gone from the office. Fourteen people and I'm the only one left at the office. So the phone rang at five o'clock and as I'm wont to do, I just hit the button and picked it up. And when I realized who it was the next sentence was, "Before you hang up, let me at least get my story out." And so we began to talk and Dr. Paul was persuasive. I went down and talked with

him. I was very candid about where I was professionally and academically, what I wanted to do. He was very candid about what they were looking for. They had been looking for eighteen months and hadn't found someone. And I agreed to come on board and then began to start rotating my different projects off. SAMM was the last one because it was the hardest, because it was like giving up my child.

DAN ROYLES: What was the position they were looking to fill?

VICTORIA CARGILL: They needed someone to fill an epidemiology slot and that's what I was trained to do here at Penn. But when I got to the NIH it became clear, because Dr. Paul had told me he would be leaving and going back to his lab, that the epidemic was really bursting forth in communities of color and the Congressional Black Caucus was becoming increasingly unhappy about how the epidemic was emerging. And there were a lot of questions about what were we doing in our research and outreach portfolios to address this need. So although I had originally come on to be an epidemiology person, Dr. Neal Nathanson, who actually I first met when I was a fellow here and he is back here, said to me, "If epidemiology, strict numbers crunching, isn't what you want to do, what would you like to do?" And I said, "You know"—in complete naiveté—"I think I'd like to be the minority AIDS czar." Thinking, Okay I can look at our portfolio gaps and I can see what are the areas [00:36:00] that we need to address and that will make sense. And I can continue to see patients, fine. Literally the day after we had that conversation, the push from the Congressional Black Caucus for the declaring of a state of emergency in HIV/AIDS in African Americans burst forth and I remember waking up and going to the computer to see what was waiting for me in the office and going, Oh my goodness. I literally had fifty

stacking emails just about this.

DAN ROYLES: You're talking about Clinton's Minority AIDS Initiative?

VICTORIA CARGILL: Well, what came from the Congressional Black Caucus merging with several other Black AIDS service organizations and insisting upon the declaration of the state of emergency that AIDS was a crisis in Black America. And that began a whirlwind adventure that still goes on to this day.

DAN ROYLES: Before that, or just before that, or what this was in response to, what did the profile of HIV prevention research for communities of color look like?

VICTORIA CARGILL: A lot of the HIV prevention profile, it was felt—and I don't necessarily fully agree with this—but it was felt, looked like they were interventions adapted from those that had worked in Caucasian communities, and perhaps less of a focus on what was unique and needed to be done that was contextually and culturally appropriate for African American communities. That was one. The second was there was really not very much, if any, focus on Black men who have sex with men, which as you know has emerged as a huge piece of the epidemic. The other was just a gross disproportionate impact. You had large numbers in women, especially black women, and women transmitting to children, and men and heterosexual men, and what about prisons where there was transmission? It was just basically, do something besides count bodies. And that was really what the point was. How can we stir up and develop infrastructure and capacity? Because one of the points that was made is [00:38:00] those organizations in our communities that are trying to address this problem don't have capacity and need capacity support. What are you doing to address that? And so all of this literally blew up about two and a half months after I arrived at the

NIH. And so here I come at the end of May of 1998, and by September of 1998 there's a crisis, some push back and the creation of a number of approaches—from the Clinton Minority AIDS Initiative and eventually the addition of the racial and ethnic populations section to the NIH HIV Strategic plan. The National Institutes of Health has a strategic plan for HIV-related research—they publish this every year—but up until 1998 that plan did not have a section that focused on racial and ethnic minorities. The plan in 1999 did, because I wrote it. Which meant I had to identify content experts, academics, people living with the infection, community consultants, pull it together and identify important objectives and strategies, and get that all down on paper and get it reviewed. And we got it done, and we've done it every year since.

DAN ROYLES: When you're talking about cultural competency and prevention, just kind of for the record, why can't you take programs that have been developed for one population and apply them to another?

VICTORIA CARGILL: Sure. Some of the programs, such as the Popular Opinion Leader program, which Jeff Kelly has worked a lot on, he taught me, I've used it a lot so I feel like I can throw stones at it since I helped do it. Popular opinion leader programs work when you have a community that is cohesive, is visible, and in some way has a contact back to that popular opinion leader so that it have normative effects. So you can switch the cultural and social norms. But what do you do about a community, for example, the house ball community? Very disparate, no two house balls are the same. The authority really lies in the house, in the parents—parents in quotes. [00:40:00] There may be a set of norms that are the explicit norms—we all embrace in HIV prevention. But as most people in house ball

communities will tell you, that works until the liquor starts and the fashion show begins and then it's on. How do you then say, "I'm going to take popular opinion leaders and transfer that when this house ball doesn't look like that house ball and everybody's got the party line, but there's another line underneath?" That approach isn't going to work. Or what do you do about women who are engaging in safer behaviors with a primary partner, but many of them have secondary and tertiary partners where that relationship is about either money or support or something else. And so, "I don't need to be safe with the primary. He's fine. But I've got to be safe with these." But it's the primary partner who might may not be monogamous or engaging in undisclosed high-risk activities. You can't just then lift an intervention and say, Okay, we're going to apply this. You need to look at things that are going to draw upon resilience as well as identify barriers and challenges, and then speak in a language that people can understand.

So for example, Gina Wingood's project, the SISTA (Sisters Informing Sisters about Topics in AIDS) project, which has now been replicated so many times it's in the compendium of effective behavioral interventions, really drew on, first, African American women have strengths, African American women have a history of being the backbone of the family, African American women know how to have fun together and support each other, and we also have to take responsibility for each other. So I actually, for my own edification, attended a SISTA training. It's a hoot! It was a lot of fun. You have to spend a fair amount of time to be trained well to be a certified SISTA expert, but one of the first things she does is she says, "We're not going to talk about HIV right here. I know that's what you all want to do. The first thing is we're going to sit and get to know each other." So you talk to the person to your right and the person to your left. Then she said, "The best we all know to get

to know each other is like this.” They turned on James Brown and it became line-dancing time. (laughs) It was amazing. [00:42:00] But they’re right because everybody loosened up. And then from there you start to work through the sessions. That may not be an intervention that would work for, let’s say, Latinas who are perhaps not used to being able to speak outside away from their males, not being sure that’s not going to come back, to blow back and bite them in the back when they get back home. We actually saw this in one of our projects in Oakland where Latino men and Latinas were side-by-side in a forum talking about HIV in their community and the challenges. And the men got very upset at one point with the presenters and said, We don’t have people here who run around doing these things, and we’re taking care of our business, and you don’t know this. And the women were on the other side going like this, just shaking their heads. And when they packed up many of them came up and said, “If you want to know what’s going on in the community from our side, you come and talk to us separately. We’re not going to tell you out here in front of them because I got to go home to him. But I’ll tell you on the side.” So that’s why you have to do it in a cultural and contextually appropriate way because every community has their own norms, their own challenges, and you have to be able to address them. To just say one size fits all isn’t going to work because we’re not talking about blood pressure or diabetes. We’re talking about a disease that’s transmitted sexually and through drug use, and there are norms around that and there are sensitivities around that, which vary as much by individual as they do by socioeconomic class, culture and ethnicity.

DAN ROYLES: Have you done prevention work in the house ball community?

VICTORIA CARGILL: I’ve not done it in the house ball community. I’ve been following that

work. I know some of the investigators who have done that work. Because one of the issues that I'm concerned about is as we review our portfolio is where are our blind spots. I'm concerned we may have some blind spots in the house ball community. Just as we're looking increasingly at the transgender community because, as you know, not only is it a community that's heavily infected and impacted, but there are so many challenges to take care of that community. That's true for transgender in general, but then when you start talking about transgender of color, now we're really [00:44:00] limited by not having sufficient data to really guide us in how to effectively manage HIV risk in a trans-centric way. And that's been a concern of mine for some time and it's been highlighted as I now have two patients of color, both African American who had gender reassignment surgery. One of them had gender reassignment surgery back in the 1980s, she went to Thailand to have it done. Both of them have been HIV positive for many years.

DAN ROYLES: Where's the prevention for that community headed?

VICTORIA CARGILL: I think for that community we're having to look at a number of things. First of all, like so much of prevention now, prevention has broadened. It used to be prevention was about covering it up, stuffing something in it, and not sticking it. We're past that. Now prevention is everything from microbicides, vaccines, behavior, biomedical—i.e. treating people since we know if you drop the viral load in one you can decrease, not eliminate, but decrease the risk of transmission. But for transgender, one of the concerns I have is there are so many things that impact the individuals. Individuals have huge medical bills, which is not the case for other populations because they have to take hormonal replacement to maintain their gender assignment. Not all—in fact, many do not complete

surgery. They're gender reassigned to a point and then have stopped—again, because this isn't often covered by insurance. There are stigma issues. We hear from people that they've lost their jobs just because someone found out they were transgender and so they were fired. Although you would think that discriminatory laws would cover that, it can become very difficult. You also then have to find someone who is going to be willing to represent you.

There's issues around networks. The *American Journal of Public Health* published a study, which I think was really eye-opening and groundbreaking for many of us. If you look at certain populations with high rates of HIV infection, such as African Americans, and you look at people who have [00:46:00] low risk—meaning they rarely, or only have an occasional slip up—their risk of acquiring HIV infection is 12 times greater than a Caucasian network because the networks are so different. They're more densely compacted with few leaving but many continuing to enter. Contrast that to Caucasian social networks, people come in and people come out. In African American social networks people come in but they tend not to leave. And so you have a different mix of people and an ever-growing mix of people. And when you add to that one out three Black males is incarcerated, you can see how people's risks can escalate. But with transgender individuals, we know much less about the sexual networks, and about their sexual partners. Their sexual partners are often different from sexual partners of heterosexual men or women, or men who have sex with men. I'll go back to my patient, for example. She had her reassignment surgery done in the 1980s. She was with a man when she was a man for a decade. They went through gender reassignment surgery together. That man remained her partner as she now is physically—or phenotypically I guess is the right word—female. Then he left her. Her response to me

was, “I’m better off probably, but”—and I thought this was ironic, she was quite indignant and she said—“and you have no idea who he’s taken up with.” “I have no idea.” She said, “A trans female,” with this voice dripping with disdain and I almost wanted to say, “Well, um, excuse me but”—but I thought better of it. That’s because what it said to me was she had really made the complete transition, not just in terms of her anatomy, but in her mind. She had expressed her true identity, and for her—that was being female. She now has a female sexual partner, and is quite happy, but sadly continues to experience discrimination and stigma. So what is it about these networks that people can move in and out of like this? And who are these individuals and what’s their risk? I don’t believe we really have a good handle on that, and we need to as this strikes at the heart of effective prevention. And that’s what we’re looking at now. As well as what does it mean to have HIV infection, [00:48:00] take all these antiretrovirals, and also have to maintain all these hormones? Not so much in terms of controlling your HIV—we know we can do that—but you have HIV, you’re already at risk for getting accelerated atherosclerosis. But now you’re taking these hormones and for example—what’s that doing to your atherosclerosis? And these are the sorts of things we have to do, think about effective ways to move from prevention all the way through to management.

DAN ROYLES: Where do you think research on prevention for minority communities in general is headed right now?

VICTORIA CARGILL: I think there are a couple of places it’s headed. We’ve gotten, I think, some good traction in prevention studies that really have taken the time to find culturally, contextually, and methodologically appropriate ways to deliver messages. That being said,

we have learned that all the low-hanging fruit, that's gone. You know, the ones that were easy to reach, we got them. Now we have to get the people that are harder to reach, not only for prevention, but to link them into care and to engage them in care. So I think where we're headed is trying to use social media and social marketing because that's going to be very important. The other is looking at populations that are very transient, and Marguerita Lightfoot has done some really exciting work. She looked at kids who are runaways and throwaways and what she discovered was that, despite the fact they're runaways and throwaways, they always check their email. So what they did is they developed a program using hip-hop language and media so the kids could actually log in and start responding to actual situations. If they got it right, they got rewards that they could cash in for things they could use, but at the same time they were clearly being educated as to what they need to do to stay safe on the streets. So I think that's another example of what we're going to need to do. We need to harness technology to help us advance HIV prevention.

We clearly need to continue the work on vaccines. Vaccines has been a huge struggle and it's been a big disappointment, but we have to just keep pushing. And then we also need to continue the work at the microbicide levels. We have a number of microbicides that are out in trials. I think the biggest struggle for us with microbicides is going to be how do we get past the acceptability? Because the VOICE study, [00:50:00] like many other studies before, including COL-1492 and I was on the data safety board for that, has shown us that women will tell us one thing but they do something else. That doesn't make them any different than anybody else who does a trial, but in VOICE I think it was particularly disturbing that you had women reporting that they were using the product, like 98 percent of them said yes they used it. You had women saying yes they'd accept it, but then less than

49 percent had even any drug detectable in their blood. Any. Not at the appropriate level for any prevention, not even a smidgen. So what that says is we still haven't been able to perfect how we can do our studies so that people feel it's okay to tell us, "I don't want to do this" or "I didn't want to do it." We have a lot of social desirability bias and that's going to be a struggle when we're talking about biomedical interventions, whether they be microbicidal or antiviral. If people don't feel like they can honestly say, "No, this really bites. I'm not doing it," I think we're going to have a struggle. And we're very much aware of that. So again, spending more time looking at acceptability.

Finally, I think the last piece is looking at the long term and there is now research on the cure. It's hard to believe that we would ever say that word, and I wasn't sure that I'd see that in my lifetime, but people are looking at that. Because between the Berlin patient, we have a Bethesda patient, between the gentleman whose lymphoma leukemia was dealt with bone marrow transplant and cleared that. And now this toddler, although with the toddler I'm not as convinced. I suspect the toddler may be very early antiviral intervention as opposed to cure, but we'll see.

DAN ROYLES: The child in Louisiana.

VICTORIA CARGILL: That's right, we'll see. If her reservoirs remain as they are after five, six years, I'll be convinced. I think right now we need to wait and see.

DAN ROYLES: How has your work at NIH changed since you've been there—so, fifteen years?

VICTORIA CARGILL: Wow. I think initially a lot of my work was trying to raise people's

awareness about the need for cultural context and cultural appropriateness. There was a need to raise people's awareness about 20 percent wasn't good enough. I mean if you've got 20 percent enrollment, to say that your study's a minority study, just wasn't cutting it. I think my awareness of what policies do, in that policies really have a couple of prongs increased. It's not just the intended, but it's the unintended consequences for those who really are being impacted by a policy. And that can be good and that can be not so good. So I've learned a number of those things. I think the biggest lesson I've learned at NIH is that nothing is impossible. It may take a really long time, but nothing is impossible. When I went to NIH, if you had told me, "You know, fifteen years after you get there you're going to be looking at cure research," I would have laughed hysterically. I'm not laughing now. The field continues to change. I will always be amazed, impressed, and in awe of the resiliency of human beings to manage in the face of incredible adversity. Not only human ingenuity to look at things and to figure it out, such as Mike Cohen's HPTN-052 study, the study that showed—it was a proof of concept—if you treated the infected partner you could interrupt transmission. [00:54:00] Everyone focuses on that study and celebrates that as a way to interrupt transmission and that's completely appropriate. But remember, I'm the epidemiologist so I'm trained to look at the methods, and there were thirty-nine transmissions in that study. Twenty-eight were from the serodiscordant partner to the HIV-negative partner, but eleven of them weren't. And the reason that we know that is because Mike Cohen, in his brilliance, made sure that there was a phylogenetic tree done on every single one of those transmissions.

And you see, everyone still focuses on the twenty-eight. I focus on the eleven because, as providers, we sometimes have the tendency to see our patients and assume they're not

doing what they're supposed to do, or if you have a patient in a serodiscordant relationship and the negative partner become infected, you'll look at the partner like, How did this happen? What these eleven taught me was to remember that sometimes people aren't getting their water where they're telling you they are, so before you jump to conclusions—to make sure that both persons that are in front of you hears—hears—what you mean by preventing transmission and how that is achieved. Because I think it could be very easy to lapse into thinking, Oh, my partner's infected. They're getting antivirals therefore I'm not at risk. Well only if that person is your only partner. But if you step outside of this relationship without prevention interventions, you're at risk. And I think those eleven people remind us that we need to be very clear. Just like when we were getting transmissions or infections in vaccine studies. What does that say? That says that people heard us—You're getting a vaccine, we're trying to prevent HIV infection—but their own thinking may have been more like—I'm on a vaccine trial, it must be going to work, so I don't have to be as safe. No. Then there is an infection. So that's another important lesson that I learned.

And I think the last one I learned from my patients is that the day-to-day challenges for the people who are really between the crosshairs of this epidemic are pervasive, unrelenting and often worse than what they face with HIV alone. It's so important to realize that HIV doesn't occur in isolation but occurs in the larger context of people's lives, and I've written about some of these challenges for my patients. For example, a patient that we lost several years ago from her hepatitis C infection because she was not adherent and couldn't tolerate her medications. Her life didn't end the day that she stopped breathing, her life really ended the day that her mother was shot by her boyfriend in front of her at almost point-blank range and her having to immediately rise up as a mom to her much younger brother.

She was so traumatized by witnessing that. She protected her younger brother from seeing it by standing in front of him, and as she would tell me, “I can still sometimes feel my mother’s brains hitting my shoulder.” Now, I don’t care what hat I put on as a provider: HIV is nothing compared to having had to survive that. Obviously not all are so deeply traumatic but for so many of those living with HIV in communities of marginalized and vulnerable people, just the day to day work needed to survive is simply overwhelming, And until we can start to recognize that HIV is a multidisciplinary, multipronged problem, that you have people who live in abject poverty, you have people that have nowhere to sleep, they have food insecurity, they have parents who’ve told them all their lives, if they even had parents, You’re nothing, not going to be anything, can’t be anything. Now we’re trying to tell them, You have this infection and your life is worth saving: why? For the last thirty-plus years, I’ve been told I’m nothing so obviously it’s not worth saving. So I’ve often said to the medical students that rotate through with us sometimes the biggest part of my job is to re-parent or refocus people. If you understand that then you can understand they will test you—to see how committed you really are; they don’t show up, they act out, and you can put that in context because you say to them, Okay, you’re going through your toddler phase. Let’s move on. You’ve got to get through this. So those are a number of the lessons I’ve learned, but at the end of the day I would still say that I have been incredibly, incredibly blessed because there are few jobs that you can do, when you go home, you can look yourself in the mirror and you can say, I can sleep well tonight because I was willing to take it to the hoop for somebody.

DAN ROYLES: When you talk about needing to raise awareness for the importance for cultural context, whose awareness are we talking about?

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VICTORIA CARGILL: The investigators [00:58:00] as well as funders. And I think we've begun to really learn this well—since for example, you can't just come to the NIH and get a grant saying you're going to do a study a particular population without demonstrating any ability to work in that population, that you have relationships. That would just not be successfully funded. I think we also, talking about providers, need to understand the sociocultural context of patients we see, because sometimes it's easy to focus on what's wrong or what isn't done leading us to lose sight of what did get done and how people have managed. When I think about the patient I told you about, I can't even imagine walking in those shoes, so I once said to her, "I know that you think that I'm going to start yelling at you about not taking your pills. I'm not. I just want to say I'm amazed you can get up every day and just put your clothes on." And she said, "There was about four months I couldn't, but I had to because I had a younger brother and I know my mother would never have wanted him in the foster care or DC care system. So I had to pull it together for him."

DAN ROYLES: So you still work with patients.

VICTORIA CARGILL: Yes.

DAN ROYLES: In Anacostia. Is that right?

VICTORIA CARGILL: Yes, Southeast DC. Anacostia.

DAN ROYLES: What is the view of the epidemic like on the ground there?

VICTORIA CARGILL: When I first went to clinic in Anacostia, I felt like I had gone through a time portal and traveled back into the eighties. We'd had protease inhibitors, by '98 we had a number of protease inhibitors. By the time I started there, which was 2001, we were

pretty savvy with them. And yet I still saw people being brought in by their mothers or by their relatives that were caring for them with the blue Chucks taped to them because they had such bad mycobacterium avium complex diarrhea they couldn't keep them clean. I mean, what is this? We've learned how to prevent this. But again, it's because people either didn't come into care until late, they didn't [01:00:00] test until late, or once they got into care they didn't take their pills. Because again, there were competing needs and challenges that were far more important I'm not trying to be judgmental, I'm just saying that was the reality for many individuals at that time. I saw things I just hadn't seen in years. I came into Anacostia at a time that a syphilis outbreak was happening. I mean I saw darkfield positive syphilitic lesions on people. I hadn't seen that since a medical school textbook. I had to actually look up and ask somebody. One patient in particular I remember, because I feel very strongly that our patients need human touch, and not always with the gloves. I was talking with the patient and he said, "You've made me comfortable enough that I really need to tell you I have this problem." And he told me about this lesion on his buttocks, and so I told him to go ahead I will look at it. I saw it and I thought, I'm not sure. This doesn't look like CMV to me; it looks like something else. So I went and got my colleague, and as I turned him over he said, "Well I have actually a few further south." And we spread his buttocks to look at his rectum, I went to touch one and the director gently pushed my hand away and she said, "We'll get back to you with that." When I went outside she said to me, "That's darkfield-positive syphilis. I've seen enough of it. We're having an outbreak. Put your gloves on. Don't get it this way." And sure enough, I swabbed the lesion and did a darkfield. I have never forgotten that experience, like, Oh my goodness, this is really, honest to God, real up close and personal syphilis.

I've seen people like the patient that made me late a little bit for this interview, who have just repeatedly refused to take medication. She's only thirty-two years old and she's going to die and leave behind three children if we cannot get her to be adherent. In fact we're seeing a whole new wave of problems in the epidemic, so much so that my colleagues in Boston, here in Philadelphia, New York, Washington, Chicago—it's all the same thing. It doesn't matter and the profile is pretty similar. It's usually a female, she's usually Black, she's usually under forty, she has children, and she's very disengaged from care. In fact, so much so that when I was talking to a colleague and I said, "I just knew this woman was going to be [01:02:00] a problem because she said the fateful sentences—'I'm sick and tired of being sick and tired. I don't like taking these pills. My mother has my damn kids so I don't have to worry about that.'" And she said, "Oh and you've forgotten one: 'And nobody will miss me anyway when I'm gone.'" Now for someone to finish your sentence like that, they're seeing the same thing you are—and she practices in Baltimore. I would say in the last three years, we have lost four women like this and when she goes she'll be the fifth. And they've all been under thirty-five and they've all left behind young children. One of the ones we lost recently was so angry she wouldn't even tell us her medications. We had to basically go back to the hospital to try to find out. Her mother was in tears saying, "Baby, please talk to them." And she said, "I don't care about this anymore. I'm sick of this damn disease. I'm sick of these damn pills. I won't do this." In fact, she wasn't taking pills and we got one that fell out of her jeans pocket and I picked it up and I said to my colleague, "Oh my god, this looks like Fluconazole." And she agreed so she went back and she said to her, "Are you taking a pink pill named Diflucan or something?" She said, "Yeah."

"Why?"

“For that, I don’t know, some meningitis thing or something.”

And we just looked at each other and went “Oh my goodness. She has cryptococcal meningitis and she just basically blew this off.” We tried everything and finally the last time they came, my colleague was so frustrated she said to her, “What do you want your mother and I to do?” And she said, “To make me comfortable and leave me alone.” And that’s what she did, and she died three weeks later. And she left behind four children, the oldest one of which was eight. So as far as I’m concerned we can talk about cure in one breath, but until I can engage these women in care and treatment consistently, the fanciest drug won’t work. And for the patient that I’m going to lose, I’ve even gone as far as putting her on things like Isentress [raltegravir], a new integrase inhibitor. It’s effective and easy compared to the older antivirals. Sadly, she didn’t take that either. She just took it long enough and intermittently enough to develop resistance. When she got desperately ill we found her Truvada in her backpack, an entire unopened bottle. Since she couldn’t afford it, we had provided a stock bottle to her and yet it sat in her backpack. So these are what our challenges are going to be. Because when I say that we’ve [01:04:00] gotten the low-hanging fruit, we’ve gotten them. The people we have now are people who, for whatever reason, they’re not engaged, don’t want to be engaged, can’t be engaged, cannot muster any more reserve to engage, or are battling too many other issues like mental health or substance use. They can’t stay the course with us. And there’s one thing that successful and effective HIV care does require: you have to stay the course. Because our drugs work but we have a very wily and effective opponent—a virus that makes up to a billion copies over someone’s lifetime. With that kind of replication, when pills are not taken as prescribed, resistance is almost inevitable.

DAN ROYLES: Maybe looking more broadly, what do you think surveying the epidemic today? What do you think?

VICTORIA CARGILL: I think that we're in a good place and we're in a tough place. We're in a good place with great drugs. Our drugs can prevent transmission. We have reduced mother-to-child transmission. Back in the time when it was a horrible disease in young children, we don't deal with that very much anymore. We have made huge strides in Africa and other places. Where I think our challenges are going to be are for youth, for young men who have sex with men, and for people for whom their external circumstances do not make this number one on their priority list. It's not that people don't know; it's just really not on their priority list. And at a time where we now have an economic downturn, we're going to see people who have housing challenges, food insecurity, and that's going to drive their risk because survival sex may be one of the few ways they can manage or survive.

DAN ROYLES: So just looking back over your life so far, what are most proud of?

VICTORIA CARGILL: My goodness, that's a hard question. Because I'm not usually one to sit and go, Oh, I'm so proud. I'm proud—

DAN ROYLES: Well, now you can. (laughter)

VICTORIA CARGILL: I'm proud that I created SAMM. I think it set a number of things in motion, some of which are still in place, which I think is wonderful. It's a message that reached a lot of young [01:06:00] people and for a while held the epidemic at bay from a group of people who really were just discovering themselves. They deserved to discover themselves and not to get sick in the process of doing that. I'm proud of the fact that I

helped lead the section to develop a semblance of a plan and really put a minority AIDS agenda forward and have a number of champions in all the institutes and in multiple sectors who continue to champion this agenda. And I think I'm most proud of the fact that there are people that I met in difficult circumstances who were quite sick, many of whom, because they could pull together with a wet behind the ears internist with a big heart but maybe not the biggest toolkit, are still alive with their HIV infection. And I consider that a huge privilege to have walked part of their journey with them.

DAN ROYLES: Is there anything else that you want to say that you didn't get to say?

VICTORIA CARGILL: No, just that I hope I will not leave this planet before I have the chance to see us make really big U-turn in this epidemic, and perhaps even end it. Then I could go to sleep comfortably and get out of the way.

DAN ROYLES: Thank you very much.

VICTORIA CARGILL: Thanks.

END OF INTERVIEW [01:07:19]