

DAN ROYLES: This is Dan Royles interviewing Pernessa Seele—Dr. Pernessa Seele, thank you very much—at the offices of the Balm in Gilead in Richmond, Virginia on October 11, 2012, for the African American AIDS Activism Oral History Project. So I'll start with a pretty simple question, which is when and where were you born?

PERNESSA SEELE: I was born on October 15, 1954 in Charleston, South Carolina.

DAN ROYLES: Well, happy almost birthday.

PERNESSA SEELE: Thank you very much.

DAN ROYLES: You're welcome. So you were born in Charleston. You grew up in Lincolnton?

PERNESSA SEELE: Lincolnton, South Carolina. Lincolnton is twenty miles out of Charleston. So I was born in Roper Hospital and taken to my home in Lincolnton, twenty miles away, in the country.

DAN ROYLES: What did your parents do for a living?

PERNESSA SEELE: My mother was a schoolteacher. My father, he was an undertaker, he was a carpenter, he was a little bit of everything.

DAN ROYLES: What was your community like?

PERNESSA SEELE: My community, Lincolnton? Lincolnton was and is an all-black town. It was founded by a group of ex-slaves. When the emancipation came they got their little dollars together and bought a plot of land from the Pennsylvania Railroad and named it Lincolnville. And Lincolnton remains still an all black-governance town and that's where African American AIDS Activism Oral History Project by Dan Royles is licensed under a [Creative Commons Attribution-NonCommercial 4.0 International License](https://creativecommons.org/licenses/by-nc/4.0/).

I'm from.

DAN ROYLES: And growing up, were you active in the church?

PERNESSA SEELE: I was very active with the church. I attended Wesley United Methodist Church, but I was also involved in all church. I grew up in a time when everything was church and school, I grew up in the segregated South, so the same folks who was in school were in church. There were two churches in town—Wesley United Methodist Church and Ebenezer AME Church. But down a mile away there was Baum Temple AME Zion Church and the Pentecostal church and the Catholic Church, so I was involved with all of them. All of them.

DAN ROYLES: And what did the churches do for the surrounding community, what kind of role did they play?

PERNESSA SEELE: Well, the church was, at that time when I grew up, and it continues to be in some of our pockets although things have shifted quite a bit, the church continues to be the center of African American life. Back then it didn't matter, although we couldn't sit at the front of the bus, although there was a lot of things we couldn't do, in church we were something and everybody. The janitor was deacon, the janitor was doctor, the schoolteacher, the nurse, the doctor, none of us, whether you were a doctor or a janitor, you had to sit in the back of the bus. But when you walked into church, you were somebody. Also, the church was the same people who was your teacher during the week was also your Sunday school teacher. If someone got sick, the first line of defense was the church. If someone died, the first line of defense was the pastor was called, and the next

moment the pastor was coming, knocking on the door, or the folks from the church was bringing food. The church was just that place, it was the center for emergency. It was the center for happiness. It was the center for shelter. Whatever was needed, good or bad or indifferent, the church, the church folk—not church as a building, but church as a collection of people were there for you, and for everybody in the community.

DAN ROYLES: When you were growing up, this is obviously a period of really intense social, political change in the South. Living in Lincolnville, as an all-black town, how much did that affect your daily life?

PERNESSA SEELE: Well, it wasn't until I got older that I realized how much I was affected by it, because living in a community where I had to go outside my community to be faced with Jim Crow. I had go to Charleston or to Summerville where I had to go behind, go to the back of the Tastee Freez to order an ice cream cone or a hot dog, or I couldn't try on clothes and belts, or I couldn't try on a pair of shoes, or I had to use the colored water fountain in a park. In Lincolnville, I saw my role models. My mother was a teacher, my principal—everybody was a role model. And I was given the gift of, I was going to be somebody. There was no barriers of saying, you couldn't be this or you couldn't do this. There were no videos, there were no rap music that said anything different except, you can be all that you can be. And even though we were African Americans, or Negroes, or colored or which one of those names we were at the time, we were expected to go beyond where our parents were. We were expected to rise to the greatest level possible that we could in this country.

DAN ROYLES: So you went away to college.

PERNESSA SEELE: I went to Clark College in Atlanta, Georgia.

DAN ROYLES: Which is a historically black college, university.

PERNESSA SEELE: Exactly, um-hm.

DAN ROYLES: What motivated your decision to go to a historically black school?

PERNESSA SEELE: Well, you know, it never occurred to me to go anywhere else. My mother went to Claflin University in Orangeburg, South Carolina. She was the baby of eleven kids and only two, her and her brother, Otis, were the only two that went to college. She went to Claflin and he went across the street to South Carolina State College in Orangeburg. And my mother went and got her master's from Atlanta University. So my mother always talked about the Atlanta university complex—Clark, Spelman, Morehouse, ITC [Interdenominational Theological Center], and Atlanta University, and the graduate school. Growing up, I always wanted to leave Lincolnton. I always had a spirit of flight. I was always going to see the world, and when we grew up, the kids even now, they remind me that they used to always laugh at me because I was always leaving. We'd play hide-and-seek and I'd be talking about, "One day I'm leaving." And they'd be like, "Where're you leaving? Where're you going?" And they thought I was the craziest person in the world. And I was the only one who left when I graduated from high school. And even though folks, my family, wanted me to stay in South Carolina, I wanted to go to where my mother went to school, the Atlanta university complex. So I went to Clark College and later went across the street to Atlanta University, now they've merged and now it's Clark Atlanta. But back then there were two schools, and I went because of the influence of my mother.

DAN ROYLES: What made you want to leave Lincolnville?

PERNESSA SEELE: I always had a spirit of flight. I always wanted to. My mother was always traveling, and she always talked about distant lands, and we would get on the bus or drive Highway 301 to New York, and my mother interestingly had the opportunity when she graduated with her master's degree to go to Africa, but she chose not to go, but to come back home to Lincolnville and be a wife and a mother and a schoolteacher. And she made that decision to be home, and I could never see myself making that decision. So I grew up in the shadow of listening to my mom talk about the world that was there for me and I wanted to see it, and I've been blessed to have seen it.

DAN ROYLES: When you went to college, what did you imagine that your career path was going to be?

PERNESSA SEELE: I had no idea. During that time everybody who was going to be great was going to be a doctor or a lawyer, so I decided I was going to be a doctor. So I studied biology, hated biology, got a master's degree in immunology, hated it, because I really didn't know what else I wanted to do, although I knew by the time I graduated from college with my bachelor's I didn't want to be a doctor, but I went into research. My first job was research at Rockefeller University in New York and then I did cancer research at Sloan-Kettering. But I certainly never saw myself as the founder/CEO of an organization called the Balm in Gilead. I never knew what I wanted to do, really. But I took the science road because that's what I decided to do, and it was a great decision because now I'm the intersect of science and faith.

DAN ROYLES: So did you go to New York right out of college?

PERNESSA SEELE: Right after my master's degree. My professors wanted me to stay and do some more work. I was done and I had a vision that if I could make it in New York I could make it anywhere.

DAN ROYLES: They do say that.

PERNESSA SEELE: Yeah man, and I started singing that song. And I went to New York, didn't know nobody except a friend from college and I stayed there for thirty years.

DAN ROYLES: And so you went to work, you said Rockefeller, Sloan-Kettering. At what point did you end up at Harlem Hospital?

PERNESSA SEELE: Well what happened was, after I went to New York, I really interviewed for both of those jobs, got both of them on the same day, decided to go to Rockefeller, worked there for about six months, hated it, quit the job, went to Sloan-Kettering and worked there for about six months and quit that one because I hated it. And by then I was like, you know what, I just cannot do this research stuff. I just cannot do this laboratory stuff. Hate it. And I quit my job. In New York. With no money. (laughs) Which is why I have a lot of sympathy with young people who don't know what they want to do, because I was one of those folks. And lo and behold, I took a job working in a business school, teaching, and passing out flyers early in the morning at the subway, making ends meet. And the AIDS epidemic came on the scene, and the only thing they knew about the AIDS epidemic was it had something to do with the immune system. So with my master's degree in immunology, I was qualified to become one of the first AIDS educators in New York City. And I took a job

working in a methadone clinic at the Interfaith Medical Center in Brooklyn, New York. Because at that time the only thing they knew was gay folks and drug addicts. So I kind of ended up working in the methadone clinic. And I stayed there for, I don't remember how long, maybe one, two, three years. And then it was time to leave. My mother had passed, had made her transition, and it was time to get another job. There was this job in the *Amsterdam News* for Harlem Hospital. I knew that job was mine, but I did not want to work at Harlem Hospital. So I ignored it. Every weekend, every Friday, I'd look at the paper, saw the job. I knew it would never get filled because I knew it was my job, and I just did not go, because I did not want to work at Harlem Hospital. So about three or four weeks passed, and I said, "All right, let me just call." And I called and got an interview with Jolene Connor, and we all worked in the infectious disease, led by Dr. Wafaa El-Sadr. And I went for the interview, and she hired me on the spot. And there I am, Harlem Hospital, because I knew that job was mine. And here I am.

DAN ROYLES: So at what point did you become aware that AIDS was going to be this really dire crisis for black communities?

PERNESSA SEELE: Well, I don't know when I became aware of it. But moving to Harlem and working at Harlem Hospital was a different experience, because in the methadone clinic people came and people left. At Harlem Hospital it was a community, and I moved to Harlem. So this was three days into being in Harlem and I now have to go on the floors and see folks who are laying in bed, who are actually dying. And people really weren't really interested in the services I came to them about. They really wanted to talk. They were dying. No one was coming to see them. The family wasn't coming, the church wasn't

coming. They wanted someone to sit by their beside, hold their hand, and pray and be present with them. Personally, I didn't want to do that. I was not a pastor. That was not what I—I was afraid of people dying and I was afraid of death. So in my not knowing what to do, that was three days into this job, one morning I was getting ready for work, the third day of my job, I was getting ready for work, and not wanting to go, and I got an idea. A Harlem Week of Prayer for the Healing of AIDS. And the idea was to mobilize faith communities to do something about HIV and AIDS. And twenty-three years later, here we are.

DAN ROYLES: When you got this idea, or before you actually started the Harlem Week of Prayer, were you aware of any black faith leaders anywhere doing AIDS ministry?

PERNESSA SEELE: No. No. I was not aware of any. And I did not come to this as someone who—(pauses) let me see, how do I say this? I really, I saw the need for the faith community to be involved out of my need, not wanting to be the person at the bedside. I wasn't looking at, well where is everybody? I saw the, where-is-everybody?, and people needed spiritual support, and I needed spiritual support, too. I needed spiritual support as the care provider. So I came to it from that, not from reading a book and saying, "Oh, there's a need." I didn't do an assessment. This was like, wow. This was kind of, a light bulb went off. So no, at that time I didn't even know anybody who lived in Harlem. I had just moved there. I did not know one church or one faith person in Harlem. I just went out and went to work that morning and said, "I've got an idea," and folks said, "Well, you know we have been trying to bring the church on board and we have failed, and we don't know why you think you can do something when we have done everything we now how to do, but go

ahead. Go ahead.” And I went ahead, and literally found out who were the gatekeepers in Harlem and went and knocked on doors and said, “Hi, I’m Pernessa Seele, and we are having a Harlem Week of Prayer.” And “we” was me. And Thee. (laughs) Me and the Lord was having a Harlem Week of Prayer for the Healing of AIDS.

DAN ROYLES: What kind of response did you get?

PERNESSA SEELE: I got a positive response. The thing that was different was, first of all this was a program that was specifically designed for the faith community. It was about prayer, and healing, and education. But education was in the backdrop. If I was speaking to a community that knew a lot about prayer and healing, they didn’t know anything about HIV and AIDS. I was also bringing not just Christians, but Muslims, Ethiopian Hebrews, and everybody together to pray for the healing of AIDS. And folks were excited about it because the faith communities of Harlem, including the churches and the mosques, were already devastated. By this time I can remember the great Wyatt T. Walker, who was the pastor at Canaan Baptist Church, said, “You know, I’ve already buried forty men from my church.” And this was in ’89. So it wasn’t that churches didn’t know about HIV, they just did not know how to address it. Their members were dying, their members were suffering, their members were grieving, they themselves were being affected in their families. They just didn’t know how to address this sexual, homosexual, drug, all the issues that churches don’t talk about, it was all now in their face. And I wasn’t coming to them with a condom and a banana, I wasn’t coming to them with, “You’ve got to address homosexuality,” I was coming to them with something they knew. Prayer and healing. And I was putting AIDS education and all of the issues you have to talk about, I was putting it in a context. I was serving a

plate that they could eat. And obviously they ate it, and obviously, although I swore I was never going to do that again, here I am twenty-three years later, still doing the work of faith and HIV and other things.

DAN ROYLES: So what exactly was on that plate to make this issue palatable to those leaders? How did you take this, as you said, difficult sexual issue with all of these overtones of things that churches don't really talk about or want to talk about, how do you take that and make this something that the church can get around?

PERNESSA SEELE: Well, what I did was I placed my belief in it. I love the church, I love black folks, I love black church, I love black pastors, I love the church. And I understand black folks' relationship to the church. I understand black folks' relationship to Jesus or Mohammed or whoever they're calling on. I understand the power of prayer. It's cultural. It's historical. I understand it. So when I brought this to them, I brought it to them in a, "Pastor, prayer changes things." I brought it to them in an acknowledgment that we have a problem that we have to pray on and we have to educate because in second Timothy it says, "Study to show thyself approved." We have a situation that's facing us that we have to find a way to address. It's not okay for folks to be dying and the pastor not be a pastor. You've got to be a pastor. There are people who are grieving. We need a pastor. A pastor is different from a preacher. A preacher gets up and preaches on Sunday morning. A pastor is there with compassion. A pastor is there to listen, to support, to be there when folks are grieving. Not to condemn, but to provide a connection to forgiveness, to healing, to the compassionate understanding of Jesus Christ. We need a pastor. In the AIDS epidemic, we need a pastor. And how does a pastor be a pastor if a pastor's ignorant? So pastor, you've

got to get educated. And I can't tell you how you should address these issues. I need you to go to God in prayer, because the same God that I speak to, the same God that speaks to me, I believe, speaks to you, pastor. And we need you to go and talk to your God on how you're going to address this major crisis in our community. So we opened the conversation up to say, "Pastor, we need you to go in prayer and ask God to give you insight on how to address this issue. God's people are suffering." And I'm happy to say that when they do that they come back with, "Yeah, we've got to talk about this. Yeah, we've got to be bold and speak truth to power." And that's how we did it, really. And that's not really rocket science, and I'm sure some of your folks will not want to hear that, but when you understand the power of belief and the power of prayer, and you know that this person you're speaking to is connected to the same God that you're connected to, you ask them, you ask God, touch them. Find a way. Because we need pastors. And we need pastors who are educated. We need pastors who are ready to take a stance. We need pastors who are going to get on the front line and fight for people's lives, regardless of what their sexual behaviors are, or whether they're drug addicts, homosexuals, bisexuals, transgender, it don't matter. We need pastors who are going to stand for God's people.

DAN ROYLES: What did that first Week of Prayer look like? What events did you have, who was involved?

PERNESSA SEELE: Well, I asked folks to come to Harlem Hospital. And on that brisk October Sunday, that we were going to walk around Harlem Hospital like the folks walked around Jericho and blow the walls down. And I asked the Christians to come, and the Muslims to come and say their prayer, and the Yoruba, the chief from South Carolina came

up, and the Native Americans came, community came, and there were all these folks dressed in their own traditional garb, all of us African Americans with our diverse cultures and communities, walking around Harlem Hospital singing "What a Friend We Have in Jesus," saying our prayers in Arabic, saying our Yoruba prayers and messages, and our leaders were Bishop Quick, who just made his transition a couple of months ago, from the Christian community, Imam Rashid, who was the Islamic leader, who made his transition many years ago, Little Flower, who was a Native American leader, and Oseijeman, who was the chief from the South Carolina Yoruba village. And each of them, we had a platform outside of the hospital on Lenox Avenue, and each of them came up after we marched around, and introduced each of them. Bishop Quick was the first to come out and make a statement on behalf of the Christian community. And that day he said, "You know, I've sent a lot of people to hell. I've sent them to hell because of HIV, I've sent them because they were homosexuals, but I'm having to leave early today because I have to go to my nephew's funeral, who died of AIDS. And when my nephew got HIV, I could not send my nephew, nor could I send my sister to hell." And that was a revolutionary moment because the great Bishop Quick of Church of God in Christ stood there before the Harlem community that was filled with clergy and people from the community, stood there and said that openly. The next person to speak was Imam Rashid, who spoke about the need for treatment, the need for medicine and treatment, and to come into our community, and we needed to educate our community. And then Little Flower, she had a staff and she raised her staff up to the gods and called on the god of Abraham and everybody to come and give us divine insight on how to address HIV. And then Oseijeman, the Yoruba chief got up with all his African stuff. And I'll never forget, everybody was standing right at the platform, and he got up with

all of his African garb, and said, "I want you to know, I do not apologize for the voodoo." And when he said "voodoo," there was an energy that went *whoof*. And he called on the gods of Africa, the ancestors, to come into our community, to ascend down and give us wisdom and divine intervention on how to address this HIV crisis. And so that was the first Week of Prayer, and every day that week, that was a Sunday, we had an education program within a church or a mosque. Every day we went from a church to a mosque with some specific education program within a place of worship. So that's how we got started, through the Week of Prayer. And to the Harlem Week of Prayer, people came and said, "How did you do this?" Because they understood that if we were going to address this problem within black communities, we had to get the church involved. And people began to hear what we were doing in Harlem. So that went on, and then we took on the National Day of Prayer, and then it became the Black Church Week of Prayer, and then a couple of years ago we moved it to the National Week of Prayer for the Healing of AIDS. Today there's a Black Awareness Day, there's a Latino Awareness Day, there's the Asian/Pacific Islander Awareness Day, but all of those awareness days are modeled after the Harlem Week of Prayer for the Healing of AIDS.

DAN ROYLES: So how did Balm in Gilead come out of the Harlem Week of Prayer?

PERNESSA SEELE: By 1992, folks were beginning to call on us as if we were an organization. We were mobilizing faith successfully. And we were really an annual event. So I felt that we needed to move into a more organized structure. And we found a law firm in downtown New York, Manhattan, that said they would give us some expertise and give us a 501c(3), and I took my little self down there and he said, "Okay, what's the name of the

organization?" I said, "I don't know." And he said, "Well, come back next week." And that morning I was riding my little stationary bike because I'm always struggling with my weight, and there was a book—I don't know where this book came from—there was a book on my bookshelf called *Balm in Gilead* by Lightfoot, who was a nurse at Harlem Hospital. And I'm saying, "What am I going to call this organization?" And the spirit said, "The Balm in Gilead." And I said, "That's a stupid name. How's anybody going to know what we do if we call it the Balm?" I'm just talking to myself in my apartment, "That don't make no sense." And I said, "Okay," I'm talking to the spirit now, "If you think I should call it the Balm in Gilead, fine, but that sure don't make no sense to me." So I just know this Jewish lawyer is just going to say something, and he said, "What's the name?" I said, "The Balm in Gilead." And he just wrote it down, he didn't ask me no questions. And I said, "Wow, thank God he didn't ask me no questions." And here we are—The Balm in Gilead. (laughs)

DAN ROYLES: Did that name take on a meaning for you?

PERNESSA SEELE: Yes. When it really hit me, because I had to come to it, was when people asked me to come to church to speak, and they started playing the song. And then I was like, oh. There are many interpretations of the history, but the truth of the matter is I really didn't get it until I was introduced and every time I was introduced, the organist or somebody sang, (sings) "There is a balm in Gilead," and it was the song and the name of the organization that came together that I got it. Like, "Wow, look at this, I didn't even know we had a song." Because I was very young and crazy and stupid and just doing what I thought I was being called to do. So we have a song, and we have a scripture. In the Book of Jeremiah the prophet asks the question, "Is there no balm in Gilead?" So we have a scripture and we

have a negro spiritual, and it all wraps itself around what our mission is, and that is to improve the health status of God's people. So here you go, it all came together and I was just the catalyst of bringing it all together, but thank God those folks from Lincolnville taught me how to listen to God and how to just go with it, even though you don't know where you're going. Here we are.

DAN ROYLES: What is the significance of that hymn for black churchgoers?

PERNESSA SEELE: Well, you see, in the Hebrew book, in the Book of Jeremiah, the prophet asks the question, "Among you who believe in the one God, among you who worship this God, almighty God, why is the land, why the daughter of my people, why is the land suffering? Why is there so much suffering? Is there no balm, B-a-l-m, in Gilead?" Gilead is actually a place in Palestine. So, is there no balm, is there no healing, in Gilead? So if you fast forward that, I tend to tell the story in the context of being from South Carolina, that my ancestors in the cotton field, they couldn't read the text, they heard the text. And they created a song, which is what we do. We create songs, and they created a spiritual. (sings) "There is a balm—" So the spiritual answers the question. The prophet asks the question, "Is there no balm?" The spiritual answers the question. "There *is* a balm in Gilead." Yes, there *is* a balm in Gilead that heals the wounded soul, that heals the sin-sick soul. So the spiritual answers the prophet's question. And the organization is the action, the organization is the hands that make it all happen. So you have a question, you have an answer, and you have the hands that make the work and the activity, make it happen.

DAN ROYLES: So you incorporated Balm in Gilead in 1992?

PERNESSA SEELE: Um-hm.

DAN ROYLES: How did the work of the group change over the first, say, ten years?

PERNESSA SEELE: Well, we moved. We took our office downtown. That was a big thing because the Harlem community, they owned the Harlem Week of Prayer, and they wrapped their arms around me. I was not clergy, I was a woman, I was bald-headed, I had nothing that looked like anything that I should be doing this work. And I always give homage to those leaders in Harlem who could have destroyed this idea, because I was not of them. I mobilized them and they came and really sanctioned and gave me credit and allowed me to do this work. So I always give homage to the faith community of Harlem at that time. We moved downtown, and when we moved downtown we took an office. The great Rodger McFarlane was the executive director of Broadway Cares, and Rodger called me down to his office one day, and they had heard—him and Larry Kramer, they were best buddies—and they had heard and heard about the work that we were doing in Harlem, and Rodger called and said, “I just love this work,” because they were leading the white gay community, and I was kind of leading in Harlem the black community. And I said, “Rodger, I ain’t got no money.” He said, “Come on down here,” and he gave me an office in Broadway Cares, and gave me a salary. I was not Broadway Cares, he just helped me. So that was that, and I remember Len McNally, who was at New York Community Trust, gave us our first grant, and I remember writing our grant, that was full of all this Jesus, religious conversation, and Len McNally brought me into his office and said, “You cannot write no grant like this. This is not the way you write a grant, Pernessa.” (laughs) And he taught me how to write a grant, and New York Community Trust gave us our first grant. Then there was Michael Seltzer,

who was at Funders Concerned about AIDS, and these are all gay white men in New York, the founders of Gay Men's Health Crisis and the founders of the movement, who saw I was trying to do, and they kind of called me and said, "Hey, let me help you out here." Rodger left Broadway Cares, and when Rodger left they kicked us out and said, "You've got to move, we're not with this." And we landed on our feet at another office on 42nd Street in a little office, smaller than this one, and we grew. Mobilizing the faith community, doing the Week of Prayer, doing educational work, putting out pamphlets, and then I got another idea in 1996, and sent a cold letter to Jessye Norman. "Dear Miss Norman, I have an idea for you to do a big benefit, 'Jessye Norman Sings for the Healing of AIDS.'" I didn't have no clue. I found her publisher online, had not met her. Did not hear from her. A year later, I sent her another saying, "Dear Miss Norman, True visions never die, Miss Norman, I want you to do this concert." Then I got a call that said, "Come and have lunch with Miss Norman at the Carlyle Cafe." And by then I had some friends at Broadway Cares and I said, "Come go with me. Come go with me. I-I-It's for Miss Norman!" And I went and I had lunch with Miss Norman and she said, "Now what is your idea for this concert?" And I said, "Well, you know, I see this—" and she said, "Well you know, that's exactly my idea." And her vision for the concert was exactly what mine was. And Jessye Norman Sings for the Healing of AIDS at Riverside Church, she brought with her Whoopi Goldberg, Maya Angelou, Elton John, Anna Deavere Smith. It was just one of the greatest moments. I won a New York Emmy for Best Societal Programming in New York—(laughs) who knew?

DAN ROYLES: Had I known, I would have introduced you at the beginning of the video as "Emmy-winning Pernessia Seele."

PERNESSA SEELE: (laughs) You know what, and I really don't even remember it. Someone reminded me of that yesterday. It's been a grand journey. And then in 2000 we went off to Tanzania—went off the five African countries, really—Nigeria, Cote d'Ivoire, Kenya, Tanzania, Zimbabwe, and South Africa, and today we have an office in Tanzania. And then in 2006—in 2005 we started working on cervical cancer, and the next thing you know, I end up on the cover of TIME Magazine as one of the most influential people with the world. I still try to get my arms around that one. And you know, I stand in awe. I'm amazed, every day. I've been blessed.

DAN ROYLES: What led you to take that step to go and extend Balm in Gilead's services into Africa?

PERNESSA SEELE: Another idea, maybe? It was an interesting time because I was one of the key African Americans who were very much a part of getting the Minority AIDS Initiative. And as soon as we got the Minority AIDS Initiative, or the Minority Health Initiative, whatever it is called today. It's like a sail—we were working hard to get our country to respond to AIDS in the black community, because AIDS in the black community has always been overwhelming. It was just that the conversation was gay white men, but the epidemic was always disproportionately in the black community, as it was in the gay white community. And as soon as we got that funding, it was like a wind came and took the conversation to Africa. And when the conversation went to Africa, the conversation left HIV in the United States, the African American conversation. So the conversation went to Africa, and we were still working here at home like everybody else was, but nobody was talking about AIDS at home, everybody was talking about AIDS in Africa. My work with the faith

community took me to South Africa with the Anglican Church, meeting Archbishop Desmond Tutu and going to Uganda, meeting the archbishop in Uganda and pastors there. Then there was an RFA, CDC put out a proposal, and we wrote for the proposal to do work in Uganda. And CDC came and said, we don't want you to work in Uganda, we want you to go work in six African countries—the six I named, which included South Africa. And that's what happened. And they gave us five hundred thousand dollars to work in six African countries. Unheard of, un-heard of. And I said, "This is crazy," but I had to prove that I could work in six African countries with little or no money. And we did. And we built their capacity. It was too much, we let South African go because it was just too complicated, and we built the capacity of all five of those remaining countries, for four years, and after four years we were sustained in Tanzania. And today, twelve years later, we have a very strong national organization in Tanzania.

DAN ROYLES: What made South Africa too complicated?

PERNESSA SEELE: The politics. I can't really remember all of the pieces, but it was just hard to break through all of the—they were going through their own internal stuff, the epidemic was raging, what they believe, how they believed it, how they were going to talk about it, the politics between the CDC here and the CDC there, and now NGO—it was just a lot. And we had taken on a lot. Working in six countries with five hundred thousand dollars and you have that was just so—we were not getting anywhere. I couldn't get a call back, it was just a lot. So I wrote and asked to have South Africa eliminated from our work. Now, we still continued to work in Soweto. We worked with a coalition of Anglican churches in Soweto right up until today. We don't do that through any funding through the Centers for Disease

Control, but we're still very much a part of the South African faith community and HIV. But it was just too complicated. And I think everybody would agree that five hundred thousand dollars for six countries, or even five hundred thousand for one country, was unheard of. And we were the only African American organization that had been funded to do this work. So today we are funded by PEPFAR in Tanzania. Interestingly enough, when we went into Africa in 2000, the epidemic was raging, including in Tanzania, but today the epidemic in the United States among African Americans is in some ways worse than the epidemic in Tanzania. So we have quite a story to talk about when we look at the differences, and how the response in Tanzania and the response in the African American community, how it has been so different, and where we are in Tanzania today versus where we are in the US.

DAN ROYLES: What has made it so different?

PERNESSA SEELE: Well, the response. Our government, PEPFAR, the Bush administration did a great thing with PEPFAR and the president's emergency response to HIV. One of the requirements of getting PEPFAR money, that you had to have a national strategy. We, the United States, we just got a national strategy two years ago through the Obama administration. So whereas they have been implementing their national strategy for maybe six, seven, eight years, we're just beginning to roll out our national strategy. Whereas our funding made a concentrated effort to get people on treatment, to how do you reach down in the village, and the Balm in Gilead's work about mobilizing faith communities, you can go way down in the village and what you'll find down there is a church and a mosque. So we were very much at the table to say, "Listen, let's build the capacity of that mosque or that church to do HIV testing, to do home-based care." And they were like, "We can't do that."

And why can't you? These are folks in the village, they've been taking care of people since before the beginning of time. And they listened and said, "Okay, let's follow this route, Balm in Gilead." Whereas here, we've still got folks in this country that are still not on treatment. How could we get so many thousands of people on treatment in Africa and still can't get people on treatment here in the United States? That's ridiculous! That's ridiculous. How can the same government do such great work in Africa, do great work here—I'm not saying they're not doing great work here—but thirty years out, we shouldn't have nobody not on treatment here in the United States when we've put millions of folks on treatment in Africa. Thank God. But we could do better here at home. We could've done better here at home. That's my opinion.

DAN ROYLES: Why do you think that we haven't?

PERNESSA SEELE: Well you know, everything comes down to politics, doesn't it?

Everything comes down to politics. I believe that the high-risk people for HIV, I think the response in this country would have been quite different if white heterosexual men and white women were getting HIV, I think the response would have been quite different. I think that the epidemic, from the beginning, was addressed not from an epidemiological and a public health manner, but from a political manner. I think if we look back on how this epidemic first—if you compare the response to HIV in the early days and compare it to the response to mad cow disease or Legionnaire's disease, the way the public health responded to these diseases was quite different. They responded to HIV politically, not according to what public health, what science says you should do to contain an epidemic. But here we are.

DAN ROYLES: How does the work that the Balm does in Africa compare to the work that it does in the United States? Are there ways that the programs are different?

PERNESSA SEELE: Yes. The work in the States is building the capacity of faith communities to do this work, educating, mobilizing communities and faith to do call to action, building faith communities, their capacity to do HIV testing, to help people do treatment adherence, supporting faith communities that have health services, building health services within faith communities. That work is also happening in Tanzania, but it's happened more systematically in Tanzania. The Balm in Gilead has also been a leader working with CDC and Columbia University—Dr. El Sadr grew up in Tanzania—been the leader in home-based care, been the community organizers around HIV testing. We have taken some of our successful African American programs like Our Faith Lights the Way, a national faith-based HIV testing campaign, have adapted it, and have launched it in Tanzania. We've also learned some stuff in Africa and brought it back to the United States. Today we lead in Tanzania around some evidence-based interventions, driving, developing evidence-based interventions. We are more on the ground in a more systematic way in Africa than we are here. And I think that's because in Tanzania we have a place at the table where CDC, the Ministry of Health, the faith community, we sit at the table, and the strategy is like, okay, this is how we're going to do it. Whereas here there's a strategy, but everybody kind of has to find their piece in the strategy. Whereas in Tanzania the strategy is there and the implementation is more comprehensive and concise. Everybody understands the moving parts, whereas everybody don't understand the moving parts over here.

DAN ROYLES: When you talk about doing capacity-building work in churches, in layman's

terms, or for people who don't work in institutional development, what does "capacity-building" mean? What does that look like on the ground?

PERNESSA SEELE: That means many different things. For a smaller church who may not have ever said, "HIV and AIDS," the words "HIV and AIDS," it may be bringing in the week of prayer for the first time and educating the pastor and the leadership on what is HIV. HIV is not caught by a mosquito. There are still people who just believe that. Educating the pastor and the congregation, that's capacity-building. There's another level of capacity-building where we are helping that church form a health ministry or an HIV ministry, which means that there is now an auxiliary organization within the institution that is there to educate, that's there to help people understand their medication, is there to help the community come into that faith community, or the community is connected to the health department to help them get HIV tested. Capacity development may be linking faith communities with health departments or linking them with other health-based institutions, health facilities. That's another level of capacity. Another level of capacity may mean that a church is sophisticated now that they want to branch out and become an actual medical facility. So there are different degrees and levels of capacity development. It's depending on where we meet the faith community, where they are.

DAN ROYLES: Going back to PEPFAR, when George Bush was getting ready to announce this huge program, did you have any inkling that this was on the docket, or that this was coming down the pipeline?

PERNESSA SEELE: No.

DAN ROYLES: No?

PERNESSA SEELE: No, not at all.

DAN ROYLES: What did you think when you—how did you hear about it?

PERNESSA SEELE: Well, I'm a part of the national movement, so I've worked with President Clinton, President Bush, now President Obama, so we knew that it was coming down, and we thought it was a great thing. Of course, we needed a PEPFAR for the U.S. as well. But the Balm in Gilead's work in Africa began before PEPFAR. So PEPFAR kind of caught up with us, we didn't catch up with PEPFAR, because we had started before PEPFAR started.

DAN ROYLES: Why out of those six, then five, African countries that the Balm was working in, why did Tanzania end up being the one that's kind of the epicenter of the work that the organization does?

PERNESSA SEELE: Because in the beginning the Global AIDS Program, CDC GAP, this was all coming out of CDC GAP, and they selected the countries. And during that transition into PEPFAR, CDC also made their country offices—what's the word? The word that I need is escaping me. But they got to make their decisions. So whereas CDC Atlanta was saying, "This is going to happen," the transition came, PEPFAR came, and those offices decided what they needed in those communities. And that's before faith became involved, because President Bush really helped the world understand why faith was important to the AIDS epidemic. And each country office decided whether they were going to do faith or not. The office in Cote d'Ivoire said, "We want to really do sex workers." After three years of building the capacity of faith communities like it had never been done before, they threw all of the

resources away and said, “We’re going to do sex workers.” And each country totally ignored the vast amount of money and tremendous work that had been put in and said, “Nah, we’re going to do something else,” because they could. Except Tanzania. Dr. Cheryl Scott was head of Tanzania at the time and she understood what we were doing, how we were doing it, the important and influential role of faith communities. She saw the tremendous resource and capacity development we had done, because we had actually put a national HIV office within the headquarters of the Catholic faith community, within the Muslims, and we had done this in five countries. And in Nigeria we had brought the Christians and the Muslims together for the first time. So today, when you see these particular countries talking about interfaith work around health issues, it really began with the Balm in Gilead. No one says that today—something about being a pioneer. No one says that, but the interfaith work around health issues in these countries began with the work that we did. But those country offices, they wanted to do something else. So after the first three, four, five, four years, they did not renew our cooperative agreement, but Tanzania did, so today Tanzania has the star of being the PEPFAR country that has this wonderful faith program because they saw what we were doing in 2003 and 4 and said, “We’re going to keep this program, we’re going to continue to work with Balm in Gilead,” so they have their chests out now because they’re the PEPFAR country with the most extensive, comprehensive faith involvement doing great work around HIV.

DAN ROYLES: What has been the Balm’s involvement in the Caribbean world?

PERNESSA SEELE: We have done work around faith communities, we just did a training there in the eastern Caribbean a couple of months ago, we’ve done some training in

Barbados, but unfortunately we have not as of yet created that systematic response in the Caribbean. That's one of the things that we are yet to do. Because African Americans and Africa and the Caribbeans, I feel that we definitely need to find a way to do more work around faith communities in the Caribbean.

DAN ROYLES: Is there any factor or set of factors that has prevented the work from taking off there?

PERNESSA SEELE: No. It's just a matter of our own internal capacity and resources. That's it. We do work in the Virgin Islands, so that is a part of our piece, ongoing.

DAN ROYLES: You mentioned earlier that although the Balm started as an organization focused on HIV and AIDS, now you've broadened into other health issues affecting people in the diaspora. Why expand the breadth of the mission?

PERNESSA SEELE: Because African Americans, our health—we are disproportionately ill, we are sick disproportionately with everything. Whether it's HIV, whether it's syphilis, whether it's gonorrhea, whether it's diabetes, whether it's heart disease, whether it's cancer. We have so many health challenges. And we found that as we did this work over a period of ten years, we were really kind of, within the African American church, we were alienating folks with diabetes and heart disease, because we brought in a lot of attention with that. And one person may have everything. They may have HIV, heart disease, diabetes, and everything. So we made a conscious decision that we needed to incorporate, and as HIV becomes more chronic, more of a chronic disease, people are not just dying with HIV anymore. They're living longer, scientists are saying if you get HIV today, you probably

won't die from HIV. You may die from diabetes or cancer or heart disease before you die from HIV. So it just makes sense to incorporate, to talk about more of health ministry than to just talk about HIV. And now as we move forward, we'll be taking on more conversation on sexual violence and sexual health. Because the root of the problem, when you look at HIV and all sexual diseases, there's just too much sexual violence in our community. And the church has got to be at the center. It's like starting all over again. We cannot continue—the church, faith communities—cannot continue to be silent on issues of sexual violence. We can't do that.

DAN ROYLES: You mentioned misconceptions about the ways that HIV is spread that people still believe in and propagate. And not to say that this is necessarily a misconception or not to kind of put it in that box, but theories about the origin and spread of HIV being conspiracy-fueled in some regard are in circulation.

PERNESSA SEELE: Um-hm.

DAN ROYLES: Is that something you encounter when you're doing capacity building in African American faith institutions?

PERNESSA SEELE: Black people, all over the world, believe that HIV was created to kill them. We may not say it, we may not talk about it, we talk about it in private, but that is a fundamental myth that whether you're in Nigeria, South Africa, the Caribbean, Russia, London, wherever you find black folks, behind closed doors we think that somebody created HIV to kill us.

DAN ROYLES: Does that pose any kind of a challenge for the work that you do, though?

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PERNESSA SEELE: Not today.

DAN ROYLES: Okay.

PERNESSA SEELE: In the beginning, when people were so vocal about it. In the beginning when there was an open mic, someone would come up and say, (screams) “Hey, you’re trying to kill us!” Thirty years later, it’s subtle. Thirty years later, it may come up, but it’s not going to come up the way it used to come up. It does not promote a barrier. We are now trying to live. We have broken through the barrier of, let’s not deal with someone’s trying to kill us. They may be trying to kill us because of violence or diabetes, or eating too much pork, or whatever, not having a healthy diet. So after thirty years I believe that we have kind of silenced that myth. What we haven’t silenced is the stigma of HIV. The stigma of HIV is still raging in our community. And we know that stigma come from ignorance. We have not done a great job with educating our community. In the beginning there was a poster everywhere. Education, education, education. When was the last time you saw a poster about HIV and AIDS? You have young people who were five in ‘89, they’re thirty now. And they have not seen, they have not been approached about HIV education. They hear it from their peers, “Oh, there’s a cure!” There’s no cure. So people get their information from the internet now, and it’s not all factual. So it’s the stigma of AIDS that’s still raging. There’s the folks who still think you can get it from a mosquito and the folks who think you’ve got a cure for it, and everything in between.

DAN ROYLES: On the subject of education, you have a new organization, Every Child USA. What is the mission of that group and how does it connect to the work that you’ve been doing for the past twenty-three years?

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PERNESSA SEELE: Well at Every Child, we look at the plight of children, not only here in the US, although we're focused on here in the US, and children are suffering. Children are suffering from abuse, poverty, it's just sad. We hear so much about children abroad, but children right here at home are catching hell. And Every Child brings attention to what's happening here at home.

DAN ROYLES: When you think about, or if you think about, your legacy and what that is or will be, what do you think?

PERNESSA SEELE: I pray that the Balm in Gilead will—(intercom interruption)—okay, that's a call for (unintelligible). Thank God for edits, right? You can edit that out?

DAN ROYLES: We don't really edit the tape.

PERNESSA SEELE: I pray that the Balm in Gilead will live forever. I pray that it will be an institution that will grow, transform, but be relevant to the people that it serves throughout the long lifetime of the organization. And I pray the organization will outlive me. And that's what I want my legacy to be, that once upon a time there was a Pernessa Seele who had a little idea. That's it.

DAN ROYLES: Anything else that you want to say? I have no more questions. But if there's anything that else you want to say—

PERNESSA SEELE: Well you know, at the end of the day, when the sun goes down, and at the beginning of every morning when the sun comes up, I want you to always be reminded that yes, there is balm in Gilead.

DAN ROYLES: Wonderful. Thank you.

PERNESSA SEELE: You're welcome.

end of recording