

A C T U P
ORAL HISTORY
P R O J E C T

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Interviewee: **Moises Agosto**

Interviewer: **Sarah Schulman**

Date of Interview: **December 14, 2002**

ACT UP Oral History Project
Interview of Moises Agosto
December 14, 2002

SARAH SCHULMAN: So we usually just start, if you could say your name, today's date, the address of where we are, and how old you are.

MOISES AGOSTO: Okay, my name is Moises Agosto. Today is December 14th, 2002. And what else was it?

SS: The address.

MA: My address is 259 W. 19th Street.

SS: And how old are you, Moises?

MA: I'm thirty-seven.

SS: So I guess my first question is, do you remember the first time you heard the word "AIDS?"

MA: Yes, I do.

SS: When was it?

MA: I was in Puerto Rico at that point. The first time I heard it was through the newspapers, when they started to talk about this syndrome that was going on—the gay cancer. That was the first time I heard. I was in college—I would say first or second year of college.

SS: And did you have a gay identity at that point?

MA: Oh, yeah. At that point I had a gay identity. I had a boyfriend at that point. I was pretty much out—not to my family but within the community of gay people that were out there.

SS: So did you have any feeling that this information was going to be important in your life?

MA: You know, at that point what was interesting was that in Puerto Rico that was like a gringo thing. If I explain myself, it was something going on with Americans. And usually I had this personal policy that I would not have sex with Americans, at that point. So it was like something that was kind of far, but that was there. But it just started to come closer once you heard about it more and more in the media, and some people getting sick—but very few, because people would not talk about it.

SS: So when did it first affect your life?

MA: The first time it did, I think I had a friend. After my first lover, I started to go out with a guy who—everybody would tell me “be careful.” I just thought be careful he wasn’t going to break my heart. But he supposedly had a roommate. It ended up being his lover who was from New York. That was when a friend of mine said, “You should be careful. This is what’s going on in New York, and this person goes out with this person from New York.” That was like the first time I was like, “Hmm, this could be something.” I remember the first time I went to his house after I had that conversation. I started like to put pieces together, because he had the most complete supply of vitamins I had ever seen in my life. It was a whole closet full of vitamins. You start to think, “Why this guy has so many vitamins?” Then, you know, the more and more I thought about it, I started to feel that probably, even though he was the second guy I was seeing, I should go and get tested. At that point, the test just came out. So I thought that maybe, just to get it out of my way, that I should do it.

SS: So what happened?

MA: So I went. I went with a friend of mine, pretty sure that I was going to get it out of my way. I got some sort of counseling. We went to the first clinic that was doing

testing in Puerto Rico. Then, after the two weeks, we went to go get them back, but my friend said that he didn't want to know. So I went by myself, and there I was—positive. It was 1986/1987. They told me, "There is nothing we can do. Exercise." Ironically, they said, "Take a lot of vitamins." It was difficult, because I was young. I was starting college. It was a non-conversation among gay men in Puerto Rico. And my family also, it was a non-conversation with them.

SS: You told them.

MA: No, I told nobody.

SS: You didn't even tell your boyfriend?

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MA: No. At that point, we were not going out anymore. I told the person I was seeing at the time. And it was the only person, without thinking, "I can't tell this to anybody. What am I going to do? What am I going to do?" But I kept it to myself—just a few friends, until I came to New York. I decided I was going to move on. I mean, it was that first week of depression that I had no idea what I was going to do, who I was going to talk to, health-wise. I come from a very working-class family, so I had no health insurance—just like the one they give you in college. But I wasn't going to do that. So I kind of opted to not go to a doctor, not do anything, and just read and look what I could find.

SS: So what did you find?

MA: So one day, I am walking and in Old San Juan there is this bookstore. And I saw this book—I still have it—that said, *Living With AIDS*. It was a guy named O'Connor. And when I saw the book, imagine—after a week of depression and thinking, "Well, if cancer people battle it, maybe I can." So I knew I had to find out some way to

know about it. So I saw this book, and it was like, “Boom, my bible.” It became literally my bible. Secretively, I would read. My mind was going crazy with all these things like no eating red meat. You take all these things, like no toxins. I followed everything the guy was saying, but it was so early on. So that kept me going for a year—again, with nobody around. But after that year, I just started to go down the hill emotionally.

Health-wise, I had no idea how my health was. I wasn’t seeing a doctor. But I was going into deep, deep dark depression. I had to decide if I was going to go to graduate school, where I was going to go—all that stuff.

A friend of mine—a good, good friend of mine who unfortunately passed to AIDS. He was a professor in the university in the Department of Psychology. I didn’t know him well at that point, but I knew I needed some sort of help. I just stopped him on the campus and said, “I would like to talk to you.” He said, “Sure, what’s the matter?” I said, “I need help.” I don’t know what he thought, but he said, “Come to my office.” When I told him, he was good enough to take me as a patient for free. That helped me to start putting the pieces together. That also was the beginning of the first type of work, because he suggested there are no support groups for gay men—why don’t we start one in Puerto Rico? I said, “Whatever you get other people I can talk to, the best.” So he brought like two more guys.

SS: He was gay, also?

MA: He was gay. And he knew about AIDS, because he just graduated from Harvard and came to teach. So that last year was easier because of him and the other guys that came to the group—two other guys.

SS: And they had AIDS, also?

MA: One of them. The other one was another psychologist. And also, he was the executive-director of the AIDS group, the first one we started.

SS: What was that called?

MA: Fundación *SIDA*. So that year went. That was when I started to hear about—I remember he brought a book by Marty Delaney, and something Marty Delaney wrote. I started to hear about this group, this radical group in New York. It was like he was helping me, in my process of going to graduate school, come here and know where to connect. So I came to New York.

SS: So you came here to go to graduate school?

MA: Yeah, yeah.

SS: In what field?

MA: In literature. So the first time I got a t-cell count, I remember he helped me through a doctor in Puerto Rico. I mean, I was planning to go to graduate school, but it became more urgent because I had no health care. I had to do something. He knew through friends in Boston that I had to do something, so he connected and we got a t-cell count—my first one in two years after I got tested. And it was like 800-something. I had no idea what that meant, but the doctor said, “When you get to New York, you need to find out a way to follow up with this.” You want me to keep going?

SS: Yeah. I’m interested in how you got to ACT UP once you got here.

MA: We’re getting there.

SS: That’s okay. Take your time. We have plenty of time.

MA: So, when I applied to graduate school, all that had to do with where I was accepted. I had three choices. One was the University of Minnesota, Amherst in Boston,

Tape I
00:10:00

or Stony Brook, New York. Of course, being Puerto Rican, you take the one that is less cold. So I came to New York—and also because I had family here, and they gave me more money than the others. So I said, “Stony Brook is a good literature department. Let me just go there.” So I came to New York. I was doing my graduate school. I found a job in the Bronx, before I got to ACT UP. But you will see at some point it connects. I found a job as a literacy teacher in the Bronx—the South Bronx. It was to teach Latino women who were on welfare who couldn’t go to ESLN—English as a second language—because they didn’t know how to read or write in Spanish. So my job was to teach them to write and read in Spanish, so they could move along to English as a second language.

And this was while I am taking theory and Derrida. But I here with these women, right in Soundview, right there in the South Bronx. So it was a little transforming already in my head, the way you live your life in the academia corner while these things are going on in the real world. But it was just a process going on in my head. One day, I run into Roger Black. I don’t know if you remember Roger. He was a member of ACT UP. He lives now in San Francisco. He used to go to the YMCA, and he said, “Listen, there is a group that I want you to come to.” I said, “Why?” He said, “Well, they need somebody to translate.” I was like, “Oh, I can do that. What is the group about?” When he said, “It’s about AIDS, it’s about this, it’s about that,” I was like, “Sure, I want to go and see what is that about.” That was the first time, while in New York, I was taken to an ACT UP meeting.

SS: So what year was that, about?

MA: I got to New York in 1988. That was around 1989. It was like almost one year after I came.

SS: So had you ever been to the gay center before?

MA: I went to the gay center for CHP to get a doctor.

SS: Community Health Project.

MA: Community Health Project—they saved my life. So anyway, I go to the ACT UP meeting. I already got plugged in with CHP. And when I walked into the room in the center—I always describe it as like a religious experience, in the sense that it was so overwhelming, coming from not having people to talk to about it, to a bunch of fired-up people. You know what I mean? They really wanted to make a difference, really fighting for their lives, literally. And I could relate to them in terms of age, in terms of where I was. And I just went right in. I said, “We need to translate.” That’s how the whole thing started.

Tape I
00:15:00

SS: So what was the first thing you translated?

MA: I translated things for demonstrations. My first demonstration was the church.

SS: Stop the Church?

MA: Stop the Church. I translated—I think that a couple of things were translated. I went to that demonstration. I was blown away. You know, if you’re coming from Puerto Rico, you don’t see these things.

SS: How did you feel to demonstrate at a church?

MA: Oh, I had no problem. I had never been Catholic, so I already had my issues resolved in that department—well, not really. But at that point, I thought. You want me to keep going?

SS: Keep going, yeah.

MA: I'm trying to give you like a—so I translated signs. That was how my whole experience with ACT UP started—translating signs.

SS: Were you the only Spanish-speaker in ACT UP?

MA: No, when I got there, there was Robert Vazquez. There was Robert Garcia. There was Joe Franco. There was Fernando. But Fernando, I think, was the only one. But he wasn't translating. I don't know for what reason they asked me to do that. So I started to do it.

SS: So did you hook up with the other Puerto Ricans, first? Who did you start hanging out with when you came in?

MA: It was interesting, because I would go to the meetings. This is something about identity—I don't know if it fits here. But I am a Puerto Rican man, born and raised in Puerto Rico. So I came to this country with already an identity formed, and a view as a Puerto Rican man in which our issues have yes to do with race, but mostly they have to do with class. So you could be black. You could be Asian. But you're Puerto Rican. The point is, if you have money. You could be a black person with money and we would call you—those from like projects and working-class families—*blanquito*, which means “little white person.” You know what I mean? So that kind of mentality I came here with. So I had to learn the race politics. I had to learn, and even experience, how race politics played here.

SS: How does it play here?

MA: Oh, you know, it's like when I got to Stony Brook. My first letter: "Dear Minority Student." I got good grades, what are you talking about? That kind of—starting to see invitations like this. And when I got to ACT UP, there is a Majority Action Committee.

SS: Already in existence.

MA: Already in existence, you know. So there is the People of Color Committee. I go, "Okay, so there is discrimination because of race." You start putting pieces together. Then it started to happen to me. It started to happen with people who would stop talking to me when they found out I was Puerto Rican.

SS: In ACT UP?

MA: Not in ACT UP. Outside of ACT UP. You asked me how it played. So when in ACT UP, what was interesting was there were no Puerto Ricans from Puerto Rico that I remember. There were some people from Latin America. There were some Latinos from the States. But for a Puerto Rican, we are always in between. We are not Latin America, neither we are the United States. We are the Caribbean. But then we have this weird, bizarre relationship with the United States that sometimes excludes us from the Latin American identity sometimes. Does that make sense?

SS: Yes.

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00:20:00

MA: Okay. So coming to ACT UP, everything was foreign. Even the Latino from here was something to learn for me. It was the closest to home, but it was something to learn. I started to hang out with people from Latin America. Always that connection of language is there. But I was more interested, when I started to translate, I

was interested in translating besides signs things that were important, useful. Remember I was teaching literacy at the same time. So I was curious about the Treatment and Data Committee, but I cannot say I was a member of it because I always would go and sit in the back. I always would look at them like “Wow.” And also, I mean, my English—it was a process of adjusting to a whole new language as well. Where should I got from here?

SS: Okay, so you were going to demonstrations. You were going to the meetings. You were hanging out with the Latin American guys. And you were going to Treatment and Data, but not really participating.

MA: No.

SS: Were you on medication at that time, yourself?

MA: I started medication—I think I started taking, when AZT came out, my first count I went to 500. My doctor put me—this was like 1989.

SS: Who was your doctor?

MA: Russell—he was at CHP. I went there for six years.

SS: So did you talk to people in Treatment and Data about what kind of treatments you were taking?

MA: I would hear. I would read a lot the things that were put on the table. And I think the first person that approached me—oh, then I got more involved and I wanted to have a committee. That was the Spanish Communications Committee. Now I remember that. I think that the was the first kind of committee that its work was to—all critical information had to be translated into Spanish.

SS: Who was on that with you?

MA: Cesar Carrasco came to the group. Popo—Popo's name I will remember. Fernando, Candido, Juan Mendez, who is back in New York. Other people came and we started to do some work. But there was a need for something more political than just translations. So I remember the first minutes of the Latino Caucus. That was when Joe Franco called for something more. You know, we were translating. We were kind of like on the services kind of side, when we had some homework to do. The Majority Action Committee was there, but there was like a need for some sort of a Latino Group for the Latinos that were there. So I remember our first meeting was Robert Vasquez, Joe Franco, Robert Garcia, myself. I think Fernando was there. I forgot Fernando's last name. Cesar Carrasco, I think, was there. There were other people, and I don't remember now. But I'm sure there were others. I remember Joe. I remember Robert. I remember Robert Garcia. And that was the beginning of the Latino Caucus.

SS: Now, what about the women with AIDS who were in the organization? Were any of them in the Latino Caucus—like Marina Alvarez?

MA: There was Marina. You see, they came along with us as we started to put the group together. Actually, I think the Latino Caucus, now that I go back, also opened the door to women with HIV that were not necessarily ACT UP members, but invited them to become ACT UP members. That's how Marina, Lydia Awadala — there was another woman, Carmen Hernandez. There was a group of Latina women who came to the group and we just like formed it. I don't know of any other committee or group in that kind of race politics context.

SS: So what was the dialogue between the gay men and women who came in?

MA: I think it was—for what I remember, it was very good. At this point, I still stay in touch with Marina. I call her once in a while. Lydia, you know, passed, and Carmen passed, and Marlene Diaz. It was good.

SS: How were their issues different than yours?

MA: Well their issues, of course, had to do with issues related to women and being a Latina woman, in the Bronx, having kids, and having to deal with their disease and feeling that they have been left aside, and their issues have not been addressed, and having to deal with not just discrimination as a woman, but also discrimination as a Latino person. It will add to that list. I don't know if that answers your question.

SS: So what kinds of things did you guys propose for ACT UP?

MA: Yeah, we're getting to the touchy part, here.

SS: It's okay.

MA: One of the things that—and this is going to talk about my exit of ACT UP. We got involved—the whole group got involved with—one of the first things that was very powerful that the Latino Caucus accomplished was the Puerto Rico demonstrations.

SS: Meaning in—

MA: In Puerto Rico, when we went to Puerto Rico.

SS: Oh, tell about that.

MA: There was a majority of members from Puerto Rico, and there was this whole issue about Puerto Rico and AIDS that started to come out in the media, that Puerto Rico has been hit really bad and the health authorities there were not doing enough. And I remember, in our discussions, looking for what are the things that we should address. Puerto Rico came up. We started to do a little research, and we found

out that the National Commission on AIDS at that point was going to go to Puerto Rico. That was when Louis Sullivan came as the HHS secretary of health. And there was this summer in which a lot of activities were going to happen. So we said, “Why not? Why not go there and create an ACT UP chapter, right?” So the idea came and it was kind of welcomed. It was kind of welcomed by the floor.

We started planning around those events that were going to happen during that whole summer. One of them was the secretary going. The other was the National Commission hearings in Puerto Rico. The other was this gay pride time, even though there was not a parade at that point. And there were other activities I can’t remember. So we went. We organized ourselves, and we had to go there and organize people, because we could not fly all of ACT UP to Puerto Rico. So what we decided was that the committee was going to go—some of us—and we were going to work to mobilize people.

There were a lot of touchy issues related to me coming from there, knowing that having the Americans, or what is perceived as coming from the Americans, coming with some sort of political movement—even though it was related to health, it was political. To impose a point of view to those that were already doing some grassroots work—we had to be careful with that. I always think that is very important that, no matter how liberal you are, you cannot lose sight of that. And also, come on, growing up in a colony where you hate all these things that you have been imposed to have. So we went to Puerto Rico. It was quite a trip.

Tape I
00:30:00

SS: Who went?

MA: From the top of my head, it was the Latino Caucus and the Spanish Communication Committee. We joined forces. I remember that Jose Santini was going to go first. He was going to start setting the ground. Then Carlos Cordero and myself went like two weeks before. Then, Gilberto—I forgot his last name—and other members, Cesar Carrasco, Candido Negrón, Juan Mendez, of course.

SS: Did any of the women go, too?

MA: I think Marina went, or Carmen Hernandez went. I don't remember. So we go two weeks before. I remember Jose had—he made some advances with the media. But we really needed to move people. I remember we got there—me and Carlos—and we got to meet the AP director. So he said, “If you've got us, you've got all the newspapers.” So we told him what we had planned. We wanted to propose a plan for the government, so we wanted to arrange a meeting with the government, which we had with the AIDS czar at that point in Puerto Rico.

SS: And ACT UP paid for this?

MA: ACT UP paid for it. One of the things was that we went—it was calling people we knew. Like I called a friend who rented condominiums, and said, “Could you really help me with this?” He gave us a very cheap deal and we put everybody in one apartment. Then we would have meetings in the houses of people that would meet. And Carlos would go to the bars. Because we had a history in the community before, people know who we were—not in that capacity. We went with the “Silence equals Death” sticker, the Spanish one. And you know, we would go with our ACT UP outfits—little, short jeans and boots—and go to people, smile, and put a sticker on their chest. They

would go, “What’s this?” “Oh, you want to know?” We would say, “Come to this meeting.”

It was amazing, because then the other people came—the other ACT UP members, other Latinos, and also non-Latino members. But my memory is not that great now. We started to do the same—go out and put stickers on people, and just say, “Come on and see.” Then we knew some owner of a bar. Of course, at that point people were getting sick and dying. So he opened the bar for meetings. I remember in two weeks we had a meeting of like 200 people. For Puerto Rico, it’s like—and it was a really rough conversation to negotiate if they really needed an ACT UP chapter, or they just needed to start the fire and take it from there, and we leave. Because we were not going to stay, which was my main concern. You don’t go there and say, “You need to have an ACT UP.” Because we were not there.

So that was one of, I think, the big things we accomplished there. We had a series of demonstrations. We had one the first time Sullivan was having a meeting with the Department of Health in front of a hotel. We had like ten, twenty people, but we got media coverage. Then we had another demonstration at the commission meeting. It was all like a crescendo to get to—we wanted to do a march in Old San Juan. It all happened. We began to get more people and more people. Then, we had a pretty successful march in Old San Juan. We would say, “*El gobierno tiene sangre en sus manos* (the government has blood on its hands).” So it was pretty powerful, because it was the first time there was a very activist-like direct action taken there. So that is ACT UP and Puerto Rico.

SS: And did they end up with an ACT UP chapter?

MA: Well, they started an ACT UP chapter. It of course—and I knew this—it was not going to evolve as ACT UP. And I think what it did was that, for one year, two, some people kept meeting as ACT UP. Then other groups started with their flavor, with their needs. And even a PFLAG chapter started. For me, it was not about having a successful ACT UP chapter. It was just to set the fire up. I think it started to extend to other people that wouldn't even think to do it at that point.

SS: What about those straight groups, like the left groups or other human rights groups in Puerto Rico? Did they support it?

MA: Yes, some of them, like the AIDS organizations that were starting there, yes. But this kind of discrimination—you've got to remember, we were coming from the States. AIDS still had a big stigma attached to it in Puerto Rico. I take that back. We had a group of lawyers, and we had a lawyer that came to help us to do some research for the recommendations we wanted to give to the government. Jorge Irrizarry, from Puerto Rico, started to work with them on doing that. He was an active member in what started to be ACT UP Puerto Rico that then evolved to something else.

SS: What about the difference between gay men and IV-drug users, or people who had gotten infected through drugs? Was that tension played out in Puerto Rico?

MA: Well, we knew that most of the cases had to do with drug users, and within the gay community there was still a little wall in terms of like this stigma and people not wanting to talk about it. There was that sense of not feeling comfortable with the issue. Richard Elovich came, as well, and we went down to a place called La Perla. A couple of the members went there to do needle exchange education. I didn't go, but those that

went told me it was devastating to see what they saw there. Probably Gregg was there, I don't know. But I think Richard and somebody else were there.

SS: What about inside the Latino Caucus, between people who had been former drug users versus people who were gay? Was there any kind of discussion about that?

MA: I think the majority were gay.

SS: Right. I'm talking about the women who came in.

MA: Besides the women, the majority were gay. I think the women were the ones that would be very strong about the drug use issue. And the gays, too, but to some extent people like Lydia and Marina were the ones that kept the issue in our faces.

JAMES WENTZY: I'm sorry, we have to change tapes.

MA: Where were we?

SS: You were going to tell me something messy.

MA: Not messy. No, this is what I think was interesting with my experience with ACT UP, and my experience with the movement, and what needed to happen, and the difference mentalities and ideologies that played out in the context of the Latino Caucus, but also in the context of the whole organization. I remember that, after Puerto Rico—you know, the Latino Caucus became pretty, you know, pretty recognized on the floor. At that point, within the group, came the whole issue of accountability to Latino leaders. I think we were going to the Day of Desperation kind of thing. For some reason, some members of the Latino caucus decided that we were going to have the Hispanic AIDS Forum as a target.

SS: You have to explain why and what it was.

MA: Okay, as a target, why? There was this assumption that the Hispanic AIDS Forum was not doing enough.

SS: And who were they?

MA: The Hispanic AIDS Forum? It was the first community-based organization that provided AIDS services and prevention education to the Hispanic community in New York City.

SS: And who funded them?

MA: They got a variety of sources—government, city money, and private money. If it was a Latino group or African-American group, at that point, it was mostly city money.

SS: And who were the people who ran it?

MA: The executive-director was Miguelena Maldonado.

SS: Spell that.

MA: Miguelena—actually, she changed her last name to De Leon.

SS: That's right.

MA: Then was Maldonado, now is De Leon. So somehow, you know, there was this issue of making them accountable, right? I think at that point—I don't know if I started in PWAC, or I was doing something with Ken Fornataro on treatment information, one of those. The issue internally was that they thought that they were not providing enough prevention education, that they were not doing needle exchange, that they had to make—that we had to make—our own organizations accountable.

SS: So you felt that the Hispanic AIDS Forum was not addressing the—

MA: No, I'm not saying me.

SS: Not you, some people in the Latino Caucus were not addressing the needs of IV drug users.

MA: Right.

SS: And what about the sexual prevention?

MA: Yes, that they had weak prevention efforts. So that created tension within the Latino Caucus, and I felt pretty uncomfortable with that—not with the tension. I felt uncomfortable with making the Hispanic AIDS Forum a target for direct action. The reason why was because, having experience working in the South Bronx, already working in a community-based context of some organizations, I knew that when you had to look at the bigger picture, it was pretty dangerous in the movement to use as a target a community-based grassroots group that was trying to put services together to service the community. Not understanding the politics that played in the context of city politics, funding politics—kind of like, in my mind it was like, “No, I cannot make them a target when they have to struggle to fight for their own funding.”

SS: I understand. I have a couple of questions. Had ACT UP ever targeted any other community-based organization before?

MA: You know what, that’s a good question. I don’t remember that ACT UP ever did.

SS: And who were the people in the Latino Caucus that wanted to target them?

MA: I know that people that felt very strongly about that—I know Alfredo Gonzalez felt very strong, Jose Santini felt very strong. Marina was part of some of the demonstration with the Hispanic AIDS Forum. Most of the people felt very strong. I

think that only two people—Popo was uncomfortable and I was uncomfortable. Luis Santiago was Popo, that's his name. But the others—it was pretty strong in the Latino Caucus to do that. The first one, I went with it. But the second one, I just didn't want to have anything to do with it because I started to think about what was the work I wanted to get done. And somehow, in the context of ACT UP, it wasn't happening. You know what I mean? If I was going to go, instead of empowering agencies I was going to disempower them, and put them on the spot, and threaten their funding, and threaten their capacity to build infrastructure, I felt I wasn't accomplishing anything.

SS: So how did the rest of ACT UP respond to these proposals?

MA: The Latino Caucus felt very strong. I remember at that point the meetings were happening in Cooper Union. This is all based on my memory. I remember there was one vote for a big demonstration, and most of the Caucus members went to the floor at the front. I decided to stay in the audience, and Popo was with me there. When they proposed—when they asked if anyone has anything to say about this, I spoke out. I thought that it was not going to be a positive thing, it wasn't going to be a good thing for ACT UP if they wanted to work with these other communities. And I think that demonstration was killed. It didn't happen. It cost me a lot of friends. And also it caused me kind of to be cornered into the boys' network thing. It was a sad time, because it cost me the friends I had within ACT UP. But it also gave me an understanding of making a differentiation between what was ACT UP, what was activism and what was a movement. I think that was, for me, very important, because ACT UP just was a group that was very much needed at that point, and we accomplished a lot with the media,

getting attention to the issue. If it wouldn't be for ACT UP, we wouldn't have people from the community, and patients, participating in the science protocols.

There were so many things because of our direct action methods we were able to open doors. It was about pushing and getting them open, and let others come in, and let's just do it right. That was my whole vision of it. And at a point in which also understanding that ACT UP could not be some sort of a religious thing, even though it had a religious experience—I'm not like a dogmatic person. I was in ACT UP because, at that point, it was needed. But I wasn't going to be radical in my activities just for the sake of being radical. And also, I was getting more involved with the grassroots movement happening in African-American communities and Latino communities that was like a world apart from ACT UP.

Tape II
00:10:00

SS: What were those organizations?

MA: I was invited by the National Latino Lesbian and Gay Organization to do a training on clinical trials, because it was the first NIAID—

SS: For you to train them?

MA: For them to train me. NIAID funded African-American groups, Latino groups at a national level to look for leaders in local communities, to train them in clinical trials design because—

SS: Who made them do that?

MA: Those groups?

SS: Who made NIAID?

Martin Delaney, Mark Harrington, David Barr, Peter Staley. These were the people that started to pressure NIH to have community participation.

SS: So people from ACT UP and other groups pressured them to give money to community-based Latino and African-American groups to train people?

MA: To create a group within the AIDS Clinical Trials group that was a community group.

SS: So why would you have to be called by the Latino Gay and Lesbian Group to be trained, instead of just coming out of ACT UP, since ACT UP had motivated it in the first place?

MA: No, it wasn't ACT UP. That's the point. There were people from ACT UP, but there was also Debra Fraser-Howze from the [National] Black [Leadership] Commission on AIDS. There were people like Mario Solis, who was from the National Latino Lesbian and Gay organization. There were people like—it was not just ACT UP, but a group of people.

SS: A coalition.

MA: Leadership from different communities that went there.

SS: So what was the training like?

MA: The training was great. They identified a couple of people and invited them to come. It was just about learning about clinical trials.

SS: So they brought you to Washington?

MA: They brought me to Washington. They did a training. They gave me a pretty little thing. And then we went back home. But our duty was to go back home to disseminate that. And also that was when the community constituency group started, which brought people with AIDS as a committee within the AIDS Clinical Trials Group.

SS: So what was the first trial that you were studying, or that you had access to?

MA: I think the first time I had access to that kind of research environment/discussion/ protocol design was at the CCG. They invited me to become a member of the CCG. They assigned you committees to follow a protocol, so I went to pharmacology. That was the first bunch of protocols to read and say what I thought.

SS: So you walk in the door and Tony Fauci is there? Who was the government person?

MA: The government people were the whole NIAID Division of AIDS.

SS: Do you remember the names of any of them?

MA: Jack Killen was there, part of it. Fauci was part of it. Other people.

SS: So they take you this literature graduate, and they say here, pharmacology. So how did you learn how to evaluate it?

MA: The same way I did when I found out I was positive. First I started to go out and I bought this book, *Pharmacology Made Easy*. And also, at that point already, I was more involved in translations. I was involved with *SIDAhora*, the People With AIDS Coalition magazine. So I was translating and creating information on treatment into Spanish. At that point also, going to the Treatment and Data Committee meetings, I realized that the reason why a lot of these guys kept being healthy was because they had access to the information.

SS: The guys in Treatment and Data?

MA: In the Treatment and Data Committee. They had access to Fauci. They had access to all these people. And I started to wonder, “I want that. And I want it to be everybody else.”

SS: So what treatments were they doing at the time that nobody else was doing?

MA: I remember people were in clinical trials for DDI, 3TC when it just started. There were some studies on d4T. It was all the beginning of a non-nucleocide, and then it evolved.

SS: And at that time, what were most people taking?

MA: AZT.

Tape II
00:15:00

SS: Okay, so you are starting to learn everything and figure it out. Now at what point did you have enough knowledge to start to be able to critique the protocols?

MA: I think you learn as you go. I don't think there is such a thing that you go to a seminar and you get it all. There was one issue about—okay, I remember in the Pharmacology Committee there was an issue about the ACTGs. They were not doing enough trials on pharmacokinetic. That means the pharmacology of the drugs—half-life, toxicity. The Pharmacology Committee was frustrated because they were not being utilized enough, and there was a lack of data. That was when the protease inhibitors were coming in in trials. I remember that I was struck by it. It's like we don't know how this is going to affect people, the safety matters. There were all these side effects that were starting to be seen, and we needed more pharmacology information—which at the end, it ended up to be so true. So that kind of motivated me to get into the protocols and see

what was lacking there. I remember that I had to write a letter to Tony Fauci as a community person.

I would go and ask the guys from T and D once in a while, but I would try to learn, myself, as much as I could. That was a time where I realized I knew more than I thought. I always was with this kind of insecurity that I didn't know enough. It's like that feeling, I always say, when you're a person of color here. It's like you have to prove yourself twice and three times. In the treatment and research area, you have to prove yourself like five times.

SS: To the scientists or to the T and D?

MA: Both.

SS: Why was that?

MA: Because. First, you come with a thick accent. People think that if you have an accent, you're stupid. I got that a lot of times. How can I say? I was going toward politics that fit within the grassroots movement that already happened before, or at the same that ACT UP was happening was happening within the Latino community in New York, was happening in the African-American community in New York. That was where I wanted to go—communities where this was an item added to the list, communities that already were disenfranchised. I was doing activism and having a great time with it with people that never experienced that kind of discrimination. Well, some of them, but you know what I mean. Like access to care was not that much of an issue for the majority of the members who had access to Fauci, who had access to trials. They could go into the trial because they had a good doctor, while all these people that I felt more identified with didn't.

SS: Now what about most of the people in ACT UP? Did they have the same access that the T and D guys had?

MA: I don't know about everybody in ACT UP. I can't say that they did. What I knew was that the people that I knew that were working on care, and treatment, and research had that access.

SS: Well, like the discussions on the floor about medications and protocols, were they accurate to the level of knowledge of what was known?

MA: In terms of scientific?

SS: Yes.

MA: Oh yeah. I mean, information that came out from the Treatment and Data Committee was amazing. I used it all the time, definitely.

SS: So what was the impact of people from ACT UP, including yourself, on the development of protease inhibitors?

MA: I think there was a big impact, not just on the development of protease keystroke for macros inhibitors. But I think, because of AIDS activism that happened at the level of biomedical research, the whole accelerated approval process started from ACT UP recommendations in which drugs were approved based on efficacy and safety. Then, if you had phase two or phase three, with 300 or 500 people in it that proved safety and some sort of efficacy, they would give it accelerated approval before the phase three for long-term safety studies.

SS: Who were the people in ACT UP that conceptualized that accelerated approval?

MA: I think that came out—I mean, the players in that committee were the players of T and D that everybody knew. Mark Harrington was very important on this.

David Barr, Peter Staley, Spencer Cox. Jim Eigo, for God's sake, he was like the father of everything. He started the committee. It wasn't an impact just on the protease inhibitors. It was an impact on the way drugs were going to be studied and approved or made accessible to those that need it.

SS: So given all of this brilliant level of comprehension and ability to change the government, how come access was the issue that got left behind?

MA: You know, I don't want to say it was left behind, because there was an Insurance Committee. There were committees and people—the issue of access was addressed. What I am saying is, if it was appropriately addressed in the context of access in disenfranchised communities—two different things. You can have problems with your insurance, but we are talking about disenfranchised communities that historically had a very tough time with biomedical research, had a very tough time accessing good health care, and were already confronting not just AIDS but other diseases, like drug abuse, tuberculosis, and things like that. It was part of their daily life.

SS: Do you remember specific issues or proposals being raised on the floor of ACT UP and being discarded or put to the side, that would have addressed what you just raised?

MA: I don't even remember if that came up to the floor. And if it did, I honestly don't remember.

SS: Would you raise that in committee discussions?

MA: I would try. But after the Latino Caucus started, and it was kind of like shaky internally, the Majority Action Committee kind of disintegrated. I think there was a sense of—and I'm going to speak for myself. I was—how do you say it—I was

frustrated with the lack of will to do that. I was disappointed with some of the answers I would get from people, like “We can’t fix everybody’s life.”

SS: Who would say that?

MA: I don’t think that’s important.

SS: But you’re saying that that did end up being the dominant position?

MA: It would end up like a majority of the people that I looked up to because I thought the work they did was critical were not really that much into doing work related to access to care and treatment in disenfranchised communities.

Tape II
00:25:00

SS: And what was the reason?

MA: It was like hitting your head against the wall. I don’t need to pinpoint a person, but that’s how I felt. I felt that I was hitting my head against the wall. It was important work, but maybe they didn’t have enough time. What they were doing was amazing, but we needed, somehow—if we were to call ourselves the activists in the movement, that had to be part of it.

SS: But what about the big campaign to change the CDC definition so that women would be eligible? That was a significant campaign.

MA: It was a significant campaign, and it was driven by women in ACT UP. You see, if it weren’t for the women that got involved and then pushed their issues through—because you remember, you had to push your issue through. It was not you come and everybody understands. There were a lot of heated discussions about women issues, about people of color issues. But again, it had to be driven by those people affected. If it were left to the hands of those that had the power within the organization—do you understand what I mean? As an organization, things happened in

ACT UP because of the collective effort of specific groups that pushed for their agenda within ACT UP. Does that make sense?

SS: Yes.

MA: And the same way I found myself struggling, I saw others—like women's groups—struggling for their issues. That doesn't mean wonderful things didn't get accomplished—which they did—but it was because of the force of those internal groups in the organization. Which, if you think about it, it was beautiful to see. It is what democracy should probably—it was beautiful to see that people would bring their issues. Some people would not understand them. And it was there, it was there, it was there until it would somehow click and we got something accomplished. But it wasn't a flow of total openness to all the issues that needed to be addressed.

SS: So you became an insider. You're sitting on government committees, and you're really starting to understand the treatment issues. How are you translating that information back to your community?

MA: That was when I was editor of *SIDAhora*. So I used that as a platform.

SS: What was their circulation?

MA: United States and some countries in Latin America.

SS: I mean how many?

MA: This is 1991/1992—a couple of thousand. We had a big mailing list. So that was a platform. Also, I started to work with other groups outside, like the Latino Commission on AIDS. We started a group called Latino Treatment Issues Group. We started to do small community forums in the community on treatment. From there, what was burning in me was the need to address treatment issues in communities of color. It

was going to be a big, big issue that nobody was paying attention. And even within the leadership of communities of color, it was—I remember going to Reggie Williams and saying, “Reggie, we need to do something.” Reggie passed. I loved him. Loved him Reggie said, “That’s a white boy’s issue.” I go, “Oh, no.” You know what I mean? Even there it was a process of looking at the leadership of communities of color that were already looking with a skepticism at ACT UP to address certain issues.

SS: So you think that when community-based leaders in organizations of color started to realize that ACT UP had a racial or class bias, that it may have kept them from getting treatment information or participating in the treatment discussion?

MA: Yeah. Yes, definitely. Even internally, the politics were always tension between people trying to make a space on the table for advocates of color in the arena of treatment and research. I don’t know if this is coming out right, it’s just coming out the way it is.

SS: So did you stay in ACT UP, or where did you go at that point?

Tape II
00:30:00

MA: No. I think by 1992/1993 I just didn’t—I was already working at PWAC. I was already involved on committees with the NIH. I was involved with the National Latino Lesbian and Gay Organization. I was spreading myself out to other groups—Latino Commission on AIDS. I just decided that I needed to have—I couldn’t be radical just for the sake of being radical. There was something that needed to be done and I had to look for other platforms or places that I could see that happen. That was when I went to Washington, and I went to the National Minority AIDS Council, which was an interesting transition as well. I told the executive director, “You need to do

something about treatment and people of color.” He said, “Come.” Within the ACT UP culture, it is interesting to see that for some people going from ACT UP to a CBO was kind of a little bit of becoming an insider. From a CBO to a national organization was even—you know.

SS: Who criticized you for that?

MA: People would make comments, like “From the streets to the inside.” I have been called an AIDS career person.

SS: Where do you think, of all the places you’ve worked, you were the most effective?

MA: I think at NMAC.

SS: What is that?

MA: National Minority AIDS Council. ACT UP was my formation thing. What ACT UP gave me is invaluable. I learned, and I learned, and I learned not to be afraid. I learned to speak out. I learned to work in teams, to work with other people, to connect with that human thing. AIDS made us be more human. I don’t know how I can—it just connected me to the human side, and to see and understand how AIDS first was a personal issue. First it was about me, then it wasn’t just about me. It was other guys, too, and other issues with other problems. Then it was about other people in other communities. It’s kind of like you go, and it’s still about you, but the picture keeps getting bigger, and bigger, and bigger. And I think NMAC was the place that I had the opportunity to feel I was doing something concrete that was creating an infrastructure for treatment education, treatment advocacy for these communities.

SS: But now, when you make a treatment decision, where do you go for information for yourself?

MA: For myself? I got to WebMed. I got to Project Inform.

SS: So you're not involved with TAG anymore?

MA: No.

SS: Do you mind telling us what meds you're taking?

MA: No. I'm taking Kaletra, which is a protease inhibitor, combined with Norvir, together. I am taking Ziagen and an RTI. I am taking Zerit. I am taking Hydroxyurea. And I take acyclovir. Those are my AIDS meds. And then there's the rest.

SS: Let's change the subject. The social life of ACT UP, because that was a big part of ACT UP—

MA: Oh, that was great. That was the best.

Tape II
00:35:00

SS: So how did you plug in socially to ACT UP?

MA: That was when I told you of religious experience. The beautiful thing about ACT UP, that I miss so much now, was the sense of camaraderie, not just on the political side, but also in a community/personal side. We knew how to have fun with what we did, because our hearts were three 300 percent. But also, there was no judgment, to be a naughty boy, or to have fun and go out dancing. Even I remember those couple of fundraisers for ACT UP in the Pyramid. So in terms of social life, it gave me a very strong social structure in New York. If it wouldn't be for ACT UP, it would have taken me a long time to find a family of friends in New York. ACT UP gave me that in a very—it was not a shallow way. It was a very here, in your face, real-life, and these are

your friends, and these are your friends that are dying, these are your friends that are getting sick with you. And fun. It was fun. We would go out and do a demonstration, and then we would go out and party. Any kind of thing you could think of would happen. There was no judgment.

SS: So when it came to sex, how did it break down HIV-positive and HIV-negative inside ACT UP? Was that an issue?

MA: Interesting. You know, I never had any bad experience with any ACT UP member that I had sex with. Everybody was pretty much very cool about it. And everybody that was—I don't think that it played out for me in a negative way.

SS: Did people have safe-sex in ACT UP?

MA: Gee, I don't now about everybody. I know I did. I know that sometimes you make your choices with other positive—you make your arrangements. So some yes, some no. I don't know about everybody. I know about me.

SS: What about these things you were talking about before—racial difference, class difference. When it comes to sex, was that a factor inside ACT UP?

MA: Let's see, how can I—you know, let's not be naïve. There was a little bit of that, of making exotic something. There was a little bit of that. I experienced that personally sometimes, in which—yeah, the whole thing about being Puerto Rican has had a weight. And I think that the whole racial and political thing played out also with sexual politics, if you want to call it that way. Being expected to respond in certain ways based on your sexual—I was pretty careful, though. I had a lot of sex with a lot of people in ACT UP, but there were certain people that I very much purposely didn't want to have sex with.

SS: Because?

Tape II
00:40:00

MA: Because they had power. They had power within ACT UP, and I wanted to make sure that sex was not in the equation when I had to ask for something.

SS: I understand that. We are going to change tapes.

MA: Is this making any sense?

SS: Totally.

Tape III
00:00:00

SS: So, one of the things about being in ACT UP was that people were constantly getting sick and dying—constantly.

MA: Right, constantly.

SS: How do you think that affected you personally, and also in terms of your work, knowing that people you were working with were constantly going through that?

MA: It just made me—well first, it was confronting that at a very early age and a time at which you don't talk about people dying, or you don't have friends dying. Being here in New York, and having coworkers, where I worked in PWAC, and having my dear friends in ACT UP getting sick and dying, it really affected me in the way I looked at the future. I remember that it got even to a point of non-comprehension, even though I knew—I had kind of a breakdown in 1991, when my best, best friend died in Puerto Rico. It was a period of time in which every week, every week, there was a coworker that died, there was a friend that died, there was a volunteer that died, there was another friend that was in the hospital, there was another friend that needed this, there was another friend that needed that. There was this sense of, like, we had no future. I couldn't look that further to the future, because everything was just falling apart around

me. But at the same time, I think it just gave me some sort of a—I just kept going, kept going, kept going, kept going, kept going, kept going. And I saw it in other friends. I saw it in myself. Just keep working, working, working, working, working, work, work, work, work to a point where you get sick and then you go.

SS: What about, like in ACT UP there were a lot of people who were doing cocaine, or there were people who decided that garlic was going to cure them? People were making various decisions. And when you saw your friends making decisions that you thought might have consequences on their health, did you talk to them about it? How did you relate personally?

MA: Can I explore your question and see where you're going? Are you talking about people making the choice of going into recreational drugs just to get away from it? Are you talking about Jon Greenberg and the Alternative Therapies Committee?

SS: I'm talking about a lot of different kinds of decisions. Like you made a decision to become maximally informed about pharmaceuticals and to pursue that path, and here we are. We're talking today. And people who we know—you've mentioned Robert Garcia, a lot of people that we knew—either did not get as informed about their drugs, or chose a non-pharmaceutical path. Many of those people died. Or they just decided to blitz out. I mean, I think Robert had a time like that, whatever. So how did you deal with that with people who you were close to, who you saw were making decisions that, from your information, were not going to—

MA: In ACT UP, not now.

SS: In ACT UP, not now.

Tape III
00:05:00

MA: In ACT UP, I think that the whole spirit of non-judgmental, open-minded mentality, I think gave me kind of a strong sense of respect for peoples' choices, and not to judge what they were doing. I remember nobody knew exactly what we had to do. example, with Robert Garcia, I never knew why he—while for me, the whole treatment issue was so critical. For most of the other Latinos, I would say it was not. And you know I think it has to do—and Dennis De Leon said this once, and this is why identity just comes always and plays a role. The fact that I was born and raised in Puerto Rico gave me the sense of entitlement, and a sense of “what do you mean I cannot ask for something?” When, for what I have experienced with my family in New York, or disenfranchised communities, this internal programming that haunts you forever, in which this is your destiny. You are growing up with being a minority, with a kind of fatalistic kind of attitude. I don't know if with Robert or Joe that was the case. But I think I always respected peoples' choices. I remember Jon Greenberg was a perfect example of it, who I admired and respected, because he was so smart. And for me, I would combine. Then it was funny, because you would see someone doing just alternatives and die, and someone doing just clinical trials, and die. So my approach is I have tons of vitamins and I have tons of drugs. And I try to live as healthy as I can. In terms of the path that others decided to take, there is so much that you can control.

SS: And within the Latino guys, did you discuss this openly—the issue of empowerment, and right to understand, and that kind of thing?

MA: Yes. And some people bought into it. Some people just kept going on their own, whatever they wanted to do. For me, information saved my life. So that is why I thought my duty was to make sure others would get it.

SS: So what are you doing now?

MA: Now, I went to the gray side, they call it. I worked for a group called Community Access. We do patient education. I develop the programs. But we are for-profit, we are not a not-for-profit. Our clients are pharmaceuticals, as well as the National Minority AIDS Council, or the National Association of People with AIDS. What we do is, all our programs are non-branded and non-promotional. So it is more awareness programs. So I develop and implement the educational things.

SS: So you're fulfilling the vision that you had.

MA: Yeah. I feel pretty—yeah, I fulfilled my desire to see ways of people getting information.

SS: So in your assessment, where are we now with AIDS?

MA: We are in a very bad place. This is where I get into this—we are, I think, in the most dangerous place, because it is that place in the epidemic in which people are tired. The younger generations that are in the place of, or have the ability to promote change were not exposed to what we were exposed to at a human level, which was having our friends dying. It was just waiting for us to start to get sick and die. For some reason, that is not—you ask someone twenty-something if they have met someone that died of AIDS, and I am amazed how many people say no. So politically, I think, with this administration we are back to where we were when Reagan was in power. But what I think is more outrageous is that this administration is daring to tell AIDS advocates and AIDS workers in their face that they are going to do what they want, and if you don't like it you can just go. And if you don't go, we'll put you out.

I think the rates of transmission are telling you there are other problems within our community, the gay community, that need to be fixed, and dealt with, and talked about. They are not just AIDS, but also drug abuse. This is not just a people of color issue. This is an issue in our backyard. There is no leadership development. There is no nurturing of leaders now. I don't see that happening. For example, I was on the board of GMHC and I was the youngest. And I am thirty-seven years old. So I think that this conservative agenda, this ideology from this administration of abstinence, and whoever doesn't get in that kind of ideology will be pushed out, we will audit your agency. And they go, and they do it. They clean out the advisory council for the president and bring all the people that think their way. And they dare to tell the public and media that that is normal practice for any government to put on their advisory board people that think like that. From what I learned about democracy, that has nothing to do with it.

The whole perception that AIDS is now manageable, the whole lack of leadership, lack of fire, that is—I see my own friends struggling in Washington. I had Miguelina Maldonado saying—we were talking about this, how frustrated she is—we need ACT UP again. This is the person I was talking about. She said, “It's out of control.”

SS: Do you think it's possible?

MA: I feel everything is possible. That's something I always—and I think, if not ACT UP, and it probably should not be ACT UP, but we should start mobilizing students, young people, because those are the ones that are going to be...the decisions that are made now are made for them, their children, and the children of their children. If they don't realize that that is happening now, it is going to be too late. And it's going to be horrible anyway. But if the government doesn't do what it needs to do, and we don't

start talking about sex openly among young people, and if we start to dissemble all the things that we accomplished in the past twenty years—because that is what they are doing. All the institutions and the infrastructure we built in communities of color, in the gay community, have been threatened by an ideology of conservatism that is going to not just destroy this country, but is going to destroy a quarter of the whole world population in a matter of decades.

SS: So given this view, and that you're still working in AIDS, and that you have this very dramatic view of the current situation, what would you say was the best result of what ACT UP did? And what would you say was the greatest failure, looking at it from this moment?

Tape III
00:15:00

MA: The best result of ACT UP was to unveil the curtain, was to put it in your face and make every person see the devastation of this disease. It was getting there and pushing open the door: "Look at it." There were other accomplishments, but I think that the main one was just to put AIDS on the map, to put it there, like it or not. At a government level, at an industry level, at the mainstream level, with the Day of Devastation, it put it there. I think the biggest failure was not being able to build coalitions. I think that ACT UP would have been able to build coalitions in the tradition of the civil rights movements, meaning working with breast cancer groups, working with the NAACP, working with community-based organizations, working with national organizations, I think there would have been a stronger grassroots.

SS: And do you think that that problem was from ACT UP's side, or do you think it was from other groups not wanting to be with ACT UP?

MA: It's hard to tell. I think that it was a matter of being strategic. Yes, it was a matter of being strategic. I think that at the peak of ACT UP there was an opportunity to do that. I think there were a couple of intents. But somehow, something happened that just didn't fly.

SS: What happened?

MA: I am going to speak for myself, okay. What I think happened was, at the moment, as an institution—because like it or not, ACT UP was an institution with a structure—there was a hierarchy. There were people that were powerful within the organization because of the access they had. There were committees that were more powerful than others. There were issues that were more looked at than others. That's a reality. That's the way groups function. But the groups that had less—and this is because I heard it. Those that were in the most powerful positions, that had an opportunity to bring with them that, at the time women's issues started to be raised, at the time people of color issues started to be raised, some people got confused. I am saying how I see it. I am trying to translate it into words. Some people got confused in taking ACT UP as a religion, the strategic part of it, dealing with the issues as a threat to what they had to do. And that's when they split, and other groups were formed, like TAG. I don't know if it was because of that reason, but it was—

SS: Wait, I'm not clear what you're saying. What's the reason for the splits?

MA: I think that these people thought that what they do was important enough, that they were going to benefit everybody. But they couldn't understand why other people within the organization thought, "Yes, let's say treatment issues are important in

research. But if you take a treatment issue and put it in the context of the woman, this is a whole different song.” I don’t know if you follow.

SS: Yes.

MA: So when people in this area that I think was very powerful within the organization didn’t get that kind of push from these others issues, I think that it weakened the foundation of the group. Some people moved on to other places where they could feel useful, including myself. Some people stayed. It’s like when the empire is divide—divided and conquer. That is what happened.

SS: Thank you, Moises.

MA: Thank you.

SS: You covered a lot of things.

MA: I hope it was useful.

SS: It was great. I really appreciate it. I appreciate all the work you’ve done.