

# THE BODY AS AN ARCHIVE

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VISUAL AIDS ORAL HISTORY PROJECT

Transcript: Shirlene Cooper + Lucas Michael

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**[00:00:07.820] - Shirlene**

Hello. How are you doing today?

**[00:00:11.320] - Lucas**

I'm good. I'm a little bit—not nervous—I'm happy and excited that you're here. You're somebody that I always love running into you, but we never really have a moment like we're having now. So I'm getting just goosebumps because I feel it's such an honor and pleasure to be conversing with you one on one. Not in any band, nothing like that. And I look forward to hearing about your story, really, and hopefully sharing some of my story.

**[00:00:48.320] - Shirlene**

Likewise. Likewise. I'm looking forward to hearing your story as well. It's been a very hard 26 years because I was diagnosed in 1996 of living with HIV and AIDS in the very beginning. First it was I didn't know I had AIDS. My son was diagnosed with AIDS first, so I got married in October of 1991, got pregnant immediately, had my son August the 8th of 1992. Healthy, 7 pounds 10 ounce, bouncing baby boy. Beautiful pearly white skin, blue eyes and blonde hair like his dad. And he was such a joy. And a few months down the line, he start, you know, having breathing complications and getting sick, and I didn't know what was wrong with him. And I kept going back and forth to the emergency room. You know, they thought it was asthma because he was wheezing, and they thought it was he had something wrong with his lungs. They weren't sure. And then finally they said he was HIV positive. And I was like I was devastated because I was like, where did he get it from? How would he have it? Because I don't have it. What? What happened? What's going on here? And then Christmas Eve, he went into a coma, and we had up a Christmas tree with all his presents.

**[00:02:24.770] - Shirlene**

Brand new bike, little tricycle for a two year old. And we had baseball mitts and gloves and all these little boy things for him, and he never got to open his gifts. The hospital called me on January 4th, and they said, we need you to get here because we don't think he's going to make it in the next 24 hours. So by the time I got to the hospital, when I got there, he just slipped away. So you know, it's devastating for me. I just held him. He was still warm, hair was still growing a long blonde hair, so I thought there was still life in him. So I was in denial. I couldn't believe that he was gone, that he was dead for a while and they kept telling him, put him down, put him down. I didn't want to put him down. I just wanted to hold him a lot longer. And then I finally put him down, tears rolled down my eyes, and that was it. He was just gone. You know, when you lose a child to HIV and AIDS, it's such a devastating moment in your life, and it's hard to try to capture or picture you living yourself.

**[00:03:30.880] - Shirlene**

So I didn't want to live after that. That was it? I didn't want to live. Why am I here? He's not here. Why am I here?

**[00:03:36.390] - Lucas**

It's a point of no return.

**[00:03:37.860] - Shirlene**

Yeah, that's how I felt. Later on, 1996, I got sick. You know, I started getting fevers, just keeping these high fevers, and we didn't know why I kept getting these fevers. I went to the hospital and they finally diagnosed me with HIV and AIDS. I had zero T cells. I had a million copies of AIDS in my body. I already had also had syphilis, tuberculosis, and cervical cancer. So the doctors told me, and my family, they said, listen, we cannot treat all these things at one time, and most likely your sister is not going to make it. If she makes it to the next two weeks, she'll be lucky.

**[00:04:18.300] - Lucas**

This was what year?

**[00:04:19.620] - Shirlene**

1996.

**[00:04:21.240] - Lucas**

Wow. So it was right before the protease inhibitors. So there were no meds

**[00:04:27.220] - Shirlene**

Yeah, there was no meds to save my child. No medications at all to save my child at the time.

**[00:04:32.730] - Lucas**

And was your husband in the picture back then?

**[00:04:36.700] - Shirlene**

Yes, he was in the picture. We divorced in 1996 after battles and battles and battles. We were at war with each other, pretty much I was with him. Because I think he should have told me. You know, you should

have told me this. I didn't know that you slept with men. I just didn't know. You know, I didn't know that. Had you told me this, that would have made a difference in saving the life of a child.

**[00:05:08.490] - Lucas**

Yes, of course.

**[00:05:11.220] - Shirlene**

You know, so we fought and fought and fought. I went to jail for attempted murder, and he dropped the charges and I ended up doing one year in Rikers Island, a weapons charge. And I came home, he picked me up from Rikers Island, and you know, we talked. I hated him. Even while we were talking. And now I got to go move back in with this guy. I don't want to move back living with him. So I just took off and I went to the streets, and I went back to using crack cocaine, you know, because I didn't want to feel the loss of my son. And like I mentioned, when I finally got diagnosed in '96, I was extremely sick. They put me in a ward for people with tuberculosis because it was a multi-drug resistance. It wasn't helping. My arms went up, my neck twisted backwards, and I went down to 76 pounds. They were putting me in and out of bathtubs full of ice because the fevers were 106. Wouldn't stop. They couldn't stop the fevers. Finally, a doctor, my doctor today, Dr. Yusuf African. He's been my doctor for 26 years. He's incredible. He came upstairs to the 6th floor, to the AIDS ward, and he said, take her off everything.

**[00:06:30.860] - Shirlene**

Just take her—shut it all down. Let her body relax. Because we—I had a Dixie cup of 44 pills every day. My body wasn't responding to any medication at all. 44 pills. He said just shut it down. They shut it down and I got weaker and weaker and weaker. And then came the shingles. The shingles came, you know your body's all—

**[00:07:09.210] - Lucas**

I've had those, yeah.

—and the shingles came. And the hospital told me, well, there's nothing else that we can do for you. We're going to send you home. So I started crying cus I was like, don't send me home. I'm going to go home. I'm going to die. I got shingles. I got syphilis, I got tuberculosis. I got all these different ailments here, and you're sending me home. There's nothing home. Nobody's there but me. So my doctor, he had a colleague in another hospital in Queens, Booth Memorial, it was called at the time. And he put me in a cab and he sent me over there to them. When I arrived with his note, in the emergency room, the doctors looked at me and said, wow, this is a shame that this hospital will put you out and look at your condition.

**[00:07:38.090] - Shirlene**

They immediately started taking care of me, hooked me up with morphine because I was inflamed, I was in so much pain. The lymph nodes was red, my arms was up, my head just I didn't know whether I was going to live or die. You know, when you're facing the Grim Reaper, it's like everything is lost. Everything is lost for me, you know? And I'm so lucky today that I came out of it. It took a lot of will, a lot of hard work, a lot of strength to fight this disease that we're living with today. This pandemic is no joke. I can tell anybody. I know some of us make it look like it's a walk in a park because we get up every morning, we go to work, we handle our business, we look good, but it is no joke. And I know, you know, that.

**[00:08:23.620] - Lucas**

Oh, I mean we are the lucky ones. I mean, we are the lucky. People look at us and they feel like ... I mean the kids feel like there's nothing to be afraid of now. There are pills and all that. They don't know that A: there's no cure. You're going to be taking pills forever. And some people don't take to the pills either. A lot of people that die of AIDS, they keep dying of AIDS, people being born with AIDS. And, yeah, it's not working hard. It's like constant thinking constantly about your own mortality every day, what is my body doing? What-I wonder what my numbers are like. Every day I wake up, it's like, I wonder what my numbers are, is my viral load up, how long will I be undetectable you know? But what you've gone through is, I don't like to say miracle, because it's all due to you and your strength, really, your conviction, but it's amazing. What's amazing to me is that after going through all that, all the—.

**[00:09:42.160] - Lucas**

I don't want to repeat myself and say all the amazing things that you're doing with the woman empowerment group, like traveling all over the world on behalf of people with AIDS, HIV / AIDS. And do you see the purpose in your life? Like, do you realize what great purpose you have in your life? Because of all the people that I know, like, you're one of the people that I really admire you because you do so much for other women living with AIDS, telling your story. And I was wondering how you went from that moment of total despair. How was that transformation from meaning total despair, first when child dies, then you're almost like at the doorstep of death, right? How was the transition from that to now? To the flowering Shirlene?

**[00:10:44.020] - Shirlene**

I just knew that, you know I had just woke up one day and said—first I asked God, I said, why do you keep waking me up? Because I'm in pain. I couldn't move from my neck down when I came out of this hospital. So I'm just bedridden for two years. I can't move. I got home health aides around me. They were, oh, my God. Awful. One lady cracked the egg, chopped up some bologne, did like this, and said like this open your mouth, open, she was trying to shove it down my mouth, and tears just rolled down my eyes. And at that point, I said, God, if you get me up and you allow me to do things, use my own hands, my own feet, and do for myself again, I promise I'm gonna do the right thing this time. And then an ex boyfriend, his baby's mother, she heard about me, that I was his girlfriend. She had a child, and I had an apartment

on behalf of the HIV Aid Service Administration. Just laying in the bed every day, would visit a nurse and aides coming in and out all day long because I couldn't know.

**[00:11:50.480] - Shirlene**

She came by, dropped the child off and said, yes, since he wants to play daddy, I'm going to leave this child right here. And she left. You know, I couldn't get up. I couldn't stop her. I couldn't move or anything. So the home health aide that I had, she had two children. She didn't have a babysitter, so she would watch her two kids and this child. So I'm laying in a bed, these kids jumping all over the place, having such a good time, you know, and I can't move. They're playing with my bandages because they're draining me and draining me, 'cus you know, and they want to go outside and play. And I could not get up to get them outside to play. And I said, I have to be able to get up. This child wants to play. And if I can just stand up, maybe I can do it. So I tried to get up off the bed. The first two weeks, it was hell. Like, just one step or one movement seemed like a million miles to push your body just to go. After a while, I made it two steps, then four steps, then ten steps, then I made it to the store and back and it was a lot.

**[00:12:54.430] - Shirlene**

Shortness of breath. You know, am I going to make it? Am I going to fall down? And eventually I told myself, I'm not going to let that ambulette come and pick me up anymore. I'm going to make it to the hospital by myself. Took me forever. I got it one morning, I canceled the ambulette. I said, I'm going to walk to the train and I'm going to get on the train. I'm going to see my doctor.

**[00:13:17.240] - Lucas**

Wow.

**[00:13:17.730] - Shirlene**

And I got on—oh, my God. It was a lot because I hadn't done it in two years, mind you, I haven't been able to walk in two years. I was able to get on this train, get to my doctor and sit there. And I told him, I said, I got here by myself. And he looked at me and he was very happy. Even today, he's very happy for me. He was like, wow, you took a lot of steps. And at this time, I probably rechecked my labs. I only had 60 T cells, but they were moving very slow because of the other comorbidities, you can't become undetectable. Everybody else is undetectable except for me, because I have all these other ailments. So he said, well, what we need to do first is we need to take care of the cervical cancer. So I went, I got my partial hysterectomy. We cleared up the syphilis. They were giving me treatment for tuberculosis, rifampin, you got to get the shots every day they were coming to my home. Slowly but surely. I started getting better and I decided that I didn't want to be home every day, that I wanted to go into the support groups.

**[00:14:22.480] - Shirlene**

So I attended a support group in Woodhall Hospital, and I was also seeing a therapist. And she was great. Oh, my God, she was fantastic. And she said, well, there's funds that came available for peer education. I didn't know what it was. I said, what is peer education? She said, it's educating other people on your disease and what you went through. She said, I think you would be a great candidate for it. So I was, I told her, no, I'm off of drugs, you know, I don't think I could do it. It's not for me. I don't know. She said, listen, what you just went through, you can educate others on how to get through it. Use your story to help others get through what you got through and educate them on taking medications and how you were able to take your pills and become treatment adherence, you know 100% treatment adherence. So I went into the AIDS wards and the psych wards and I started telling my story to nurses, and the doctors was clapping. Yeah, because they couldn't believe, wow, you're alive. You're a miracle patient.

**[00:15:25.490] - Lucas**

I can't believe. I can't believe.

**[00:15:26.960] - Shirlene**

I was like, yeah, well, I got here not by the grace of God, so I'm grateful for that and the job ended in like, six months because the funds ran out. But meanwhile, while that was going on, an organization called the New York City AIDS Housing Network came into the hospital and they had did a presentation on advocacy for people living with HIV and AIDS. They were brand new organization, and they needed an outreach worker. So the guy asked me, he said, you know, you're looking for a job, why don't you come and do some outreach for us? And I said, okay, I'll come and do it. \$10 an hour. I didn't have anything else to do with my life. And I'm from Walt Whitman Houses, which is Fort Green Projects. I'm familiar with the projects. I'm also familiar with all the HIV / AIDS clinics. So I just went around with flyers, handing them out in every project throughout the Tri State and through the different HIV / AIDS clinics. And I was able to recruit 3,000 members for them.

**[00:16:23.940] - Lucas**

Wow.

**[00:16:24.560] - Shirlene**

Yeah. So I went on from there. They promoted me to organizer. Now, of course, I didn't know what an organizer was. I don't know anything about this. So they trained me through a power academy, which is people organizing welfare and equal rights. We were teaching us, educating us on politics and economics and inequalities in our communities. And that went well. Went very well. And I became lead organizer, then deputy director, then CEO of New York City AIDS Housing Network, now VOCAL New York. In that time, I did local, regional, national, and international advocacy for people living with HIV and AIDS. I've been to 46 of the United States and 36 countries so far. Yeah, I think it's five world social forums and six

international AIDS conferences. I'm about to do number seven in Montreal. I just think that once you, you know, get diagnosed with something, it's either fight or flight.

**[00:17:29.020] - Lucas**

You found a nation, you really found it.

**[00:17:31.550] - Shirlene**

It's fight or flight. And I wasn't about to fly, I didn't want to go anywhere. This disease already took my son, so I didn't want it to take me, and I didn't want it to take anybody else. Even yesterday, you know, I had a doctor's appointment. I went in there. I'm one of the long term survivors in the clinic. All of them are dead. You know, there's all new patients in there and I'm the oldest one there.

**[00:17:56.400] - Lucas**

Which, have you encounter, like, at times hostility for being so public about your status?

**[00:18:05.360] - Shirlene**

Once a guy in the clinic, he's no longer with us. He passed away. I landed on the front page of POZ magazine in 2003, a special edition. It was supposed to be the CEO of VOCAL New York, which was Joe Capestany, but he had gotten sick. So I went with the editor in chief of POZ magazine to the hospital to see him. And he was so sick, he couldn't talk. And he was just, he literally died right after we left the hospital. And she said, well, can you do it? And I was like me? And she's like, yeah, can you? So I told her, okay? I can do it. I had no idea that she was going to put me on the front page of POZ magazine. And when the catalog came out and that's why I was on the front page, I was like, wow, okay. But someone has said to me, why do you keep putting yourself out there like that? And I was like, why not? You know, I can't hide from me.

**[00:19:06.170] - Lucas**

They were trying to shame you basically.

**[00:19:07.300] - Shirlene**

Yeah, but I can't hide from me. This is who I am, with or without AIDS, this is who I am. I cannot hide from it. There's no shadow. There's no place for me to run. So if I have this, I'm going to face it head on, and anybody who's coming to me has to face it with me. And if you decide that you don't want to face this with me, it's fine. I'm okay with it. It's not your problem. It's my problem. I made a mistake. I contracted this disease on my own. I take full responsibility.



**[00:19:37.440] - Lucas**

But you know what? My father, when I tested positive, and I will forever be so grateful for him, because what he told me, it was exactly the opposite. He said, this is not your fault, and I don't think it's your fault. I don't think it's anybody's fault when they catch a virus, okay? It's a virus. Even if you were careless, it's not like you went there wanting to catch it. Nobody wants it. You know. That helped me a lot to not internalize shame and self hatred and for having it. It's not your fault. You know. It's an unfortunate event that happened. And then again, in retrospect, in my case, I feel like I think of where I am now in my life. The virus for me is like, it's a constant. So I live with it every day. It's my constant companion, in a way, and it's not my enemy anymore. It's my friend, you know. Am I happy I have it. No. But I'm happy I'm the person that I am, and I wouldn't be the person that I am without it.

**[00:20:55.660] - Shirlene**

Well, you look fabulous.

**[00:20:56.900] - Lucas**

Well, thank you. So do you, darling.

**[00:20:58.860] - Shirlene**

You know, I know you remember the days when people looked very gray, pale, you would see them today, and they were going, tomorrow, you know? HIV / AIDS has come a very long way, which is important because we have the cocktails, like you said, the highly active antiretrovirals to help us along the way. And just coming this far and being able to look human, because people were not looking human at the time, and people were going into wheelchairs, and they called it the monster. Where I came from. So we was like, well, what is the monster? Oh, it's just a new disease that's out, it's called AIDS. First they were saying only gay white males could get it. Then they were saying only IV users can get it. So I said, well, how did I get it? I'm not white and gay and I don't use needles, so I'm a black woman.

**[00:21:47.170] - Lucas**

And then Haitians also—was a backlash against Haitians. Remember in the 80s, like, people wouldn't get up, like a lot of taxi drivers were Haitians, and like some people wouldn't get on in a taxi if the driver was Haitian or "looked" Haitian. It's awful. What disease do to people, the nastiness that it brings out in people.

**[00:22:08.080] - Shirlene**

Yeah. So we fought harder and harder and harder under the Power Academy from Vocal, New York, people organized welfare and equal rights. We passed 30% rent cap. You know we cap our rents 30% because the rent was too high and housing for people were living with AIDS. I launched that campaign in

2005, took eight years to get the 30% rent cap and HASA for all passed so that all people living with HIV and AIDS can get benefits. And it's just a tough situation because when you're dealing with politics, like, I'm the first black woman to sit on the City Council's HIV / AIDS Service Administration's advisory board. I got on in 2003. That's around the same time that that magazine came out, because the City Council speaker was Gifford Miller at the time. And he asked his liaison, he said, well, we want to work on housing for people with AIDS. We need to see the type of housing they're putting people into. So he sent one of his liaisons to my house to pick me up every day for six months. And we rode around the Tri-State all the five boroughs, looking at the horrible, horrific apartments that they was putting us in.

**[00:23:21.750] - Shirlene**

Some of them didn't have ceilings, doors, and the case managers just was signing I found the person an apartment. It was that bad. So they took photographs and everything of all the apartments, and we came back. And now they have to do inspections. We also ask that the case managers who belittle you that when you go on to see a case manager, they don't want to sit next to you, talk to you, look at you like you're a leper or something, you know. Where's the training coming from? They claim the trainings are done at Fordham University on cultural diversity for people living with HIV and AIDS. A lot of them don't answer the phones. It's a lot of that going on. So the system is not perfect, but it is a system. And since I've been to 46 of the states, I know that New York is the only state that has HASA which is the HIV / AIDS Service Administration, which provides housing, nutrition, SNAP, you know, clothing, different allowances for us, it works to a certain extent, but it needs to be improved. And I've been on that board now. Oh my God, it'll be coming up on 20 years next year.

**[00:24:28.700] - Shirlene**

20 years I sit on this board. It's a non paying board. Nevertheless, it's a board and I'm sort of kind of the pit bull, because I bring everything to the forefront. We are supposed to advise you. We are supposed to guide you. You people aren't living with HIV and AIDS so you don't know what the needs are, we know what to do. We need to store our medications, refrigerators. You know the drill. We need to have our own bathrooms to keep ourselves clean. Don't stick me in no little cardboard box and expect me to survive.

**[00:24:57.540] - Lucas**

You need dignity.

**[00:24:58.810] - Shirlene**

So you know we were able to get one bedroom apartments. Even some were able to get two bedroom apartments if they have home health aides that were living to help them on. So that was working, you know, sort of kind of workable. But it's so much more to do here, because AIDS is not over. You know, I've worked with the New York City AIDS Housing Network. Vocal New York, Housing Works. I've worked with so many different organizations planting seeds and trying to shelter people with AIDS and going to

multiple countries to try to see, you know, different models on what's working over there that can work over here, because some countries are ahead of us, some are behind. You know even when I went to Caracas, Venezuela, and I got sick over there, they immediately sent me to this Cuban tent. It was like, here, medicine is available. It's free or no problem. I don't see why we don't have universal health care over here as well. You know, we supposed to be one of the richest countries in the world.

**[00:25:54.440] - Lucas**

How do you run into Visual AIDS?

**[00:25:56.160] - Shirlene**

Well, I got an invitation to come to one of their art groups, and since the third grade, I've always loved art. I've always loved art, art was my favorite subject. If you wanted to give me a gift at any point in time, I would say you go buy me an art kit.

**[00:26:09.040] - Lucas**

And do you remember who invited you?

**[00:26:11.210] - Shirlene**

Wanda Hernandez. And she's the board chair of Vocal New York. And she says they have this group called Love Positive Women, and it's where you make Valentine's Day cards. So you want to come? And she and I are pretty good buddies. So I said, all right, I'll hang out with you for a little bit. We went to the Brooklyn Navy Yard, Dieu Donne, where Visual AIDS hosts their Love Positive Woman annual paper making. And we literally made paper. So you put these screens inside the vat, different colors, purple, red, white, green, if you want a purple card. And you pull it up, shake the water off, right? Turn it over, mash it down, and then pull that up, and you got your paper wet, still wet. And then you add your little designs to it. I love you. Roses are red, violets are blue. And you put them on the card, and they dry them for you, and you get to see them in an exhibit later on. And it was so much fun. I really adored this project. I met with Alex Fialho, and he said, you know, why don't you become an Artist Member if you're really interested in art?

**[00:27:21.780] - Shirlene**

And I agreed to become an artist member. And he said, Artist Members also can receive a material arts grant. I said, what does that mean? He said, you get a \$400 grant to buy art, and you can do what kind of art project you want. So instead of doing an individual project, I've always wanted to start a women's group. So I started the Woman Empowerment Art Therapy group in my living room with eight women. I'm also a chef, a licensed chef. So that day, we made tote bags. Yeah, we made tote bags in my living room. And we had women discuss domestic violence, living with HIV, aging with HIV, triple bypass with HIV. We had different women in the room that were struggling with different issues. And it was just wonderful. And

it was like, well, when is the next one? I'm like—. So I decided I would do another one. And I told CAMBA about it, and they said, well, you can use our space because more women wanted to come, and my living room ain't but so big.

**[00:28:28.700] - Lucas**

Queens CAMBA, right?

**[00:28:30.600] - Shirlene**

CAMBA is a nonprofit organization for people with HIV in Brooklyn, New York. And we went down there. They let us use their space, and a whole batch of women just showed up. So now we got another group going. So I was like, okay, I need to let Visual AIDS know about this group and how big it is and how important and how popular it is to me that we move it forward. So I had a conversation with Esther McGowan and Alex, who are Alex was at the time, Alex was the project director.

**[00:29:01.670] - Lucas**

Programs director, programs director.

**[00:29:04.330] - Shirlene**

And Esther was, Esther is maybe the.

**[00:29:09.140] - Lucas**

Deputy director. Yeah, right.

**[00:29:12.120] - Shirlene**

She went back to her board, and they called me, and they said, let's have a meeting. We want to take this group on. So I think the next organization we met at was Harlem United and Iris House. So I invited Visual AIDS to come and see. We had a packed house. It was full of women, and we were designing masks. So the mask. The group opens for 2 hours, and I opened the group with I'm the facilitator. You have to introduce yourself and say an affirmation, meaning you have to compliment yourself. All my life, I never hear black women especially compliment themselves. So they were sitting at the table like, what should I say? I said, well, what do you like about yourself? So people started getting used to the affirmations and engaging and getting more confident about themselves and who they are and what direction they wanted to go. And then we opened up the group one hour to speak about your success or your stress. You can say, My T cells just went up, yay! You know, I just disclosed to my husband, and things are working out well, or I got a new job or someone just passed away, whatever you want to discuss for one hour.

**[00:30:19.850] - Shirlene**

And since women are chatty, I shut it down, one hour, because they can keep going once the conversation starts. And then we do, put on an art project. We painted on stained glass. We've done mask design: how do you see yourself? And you can tell by the different colors, you know, how people see themselves today, whether they see themselves in a dark space or light space. We designed our own tote bags so women can carry their bags. We've done cyanotype oh, my god. Which is amazing. We've done a barbecue in Prospect Park. We've done so many different art projects that these ladies feel like they artists now. So our motto is just to bring your creativity. You don't have to be a Picasso or Rembrandt. You know, just come on in and enjoy the art. And it's been amazing. Started out with eight. We're over 400. We're in our fifth year now.

**[00:31:15.540] - Lucas**

That's amazing.

**[00:31:16.210] - Shirlene**

And one of our first funders was Elizabeth Taylor AIDS foundation, which was incredible. It just jumped right out the window. And I was like, okay, this seems like it really needs to keep going. And we're in our fifth year.

**[00:31:28.810] - Lucas**

Amazing.

**[00:31:29.530] - Shirlene**

And it's been amazing.

**[00:31:31.860] - Lucas**

See when, I think when you started, I was in the board of Visual AIDS, because Visual AIDS has Artist Members being on the board all the time, which is great thing about the organization, because of course, if it's an HIV / AIDS organization, they need to have HIV-positive people in their board. And I remember when that was brought up in the board meeting, I was so excited about it and say, this is really a game changer because it's not just about showing art. It's about making art and making art as a healing process. It's phenomenal.

**[00:32:14.200] - Shirlene**

And the art has been healing the woman. In the very beginning, a lot of the women came in, you know, angry with a lot of stress up. All that's gone. All that is gone. You know what was kind of weird? We had

did one in the Visual AIDS office, and the men showed up, and they were like, well, we're here. Why isn't there a group for us? And I said, just give me a second. I didn't know you guys were coming. Let me ask the ladies, is it okay for your guys to come in? And the ladies agreed that they could come in, and the guys showed up. They were incredible. They were like, we want a group for us, too, so maybe we'll have a men's group in the future.

**[00:32:53.730] - Lucas**

When was this?

**[00:32:55.180] - Shirlene**

This was back in the first round. In the first year, the men showed up. They showed up at the Visual AIDS office? Yeah.

**[00:33:00.740] - Lucas**

Well, they need to get their act together and organize, it's like because you guys would be doing all the work.

**[00:33:06.160] - Shirlene**

It was crazy, and when I took photographs of them and they did some incredible art. So the men are just as good as the women, and I think they needed that for their healing process as well. And the art is healing the women. And it's just been an amazing ride to see us come as far. The mission for me now is to become national and international, which we've already done during the pandemic, COVID, we got accepted for the International AIDS Conference, which we did. We also did, Sister Love. We did Atlanta. We're also invited to come down and do Montreal this year. So we are moving in different directions, which is incredible.

**[00:33:45.360] - Lucas**

I think it's such a needed service, almost. You know, if every town, every city would have something like this, you know, it's such a healthy output. Like what you were saying about suddenly one of the women disclosing to her partner, because imagine what it must be like living without disclosing. I mean, I did it. I did it for years. I wasn't afraid, I was ashamed to disclose or sometimes I was ashamed. Sometimes I was afraid that the person would feel sorry for me. Sometimes I didn't want the person to worry about me. But at the end of the day, I think at the end of the day, it's just shame masked as other things.

**[00:34:37.360] - Shirlene**

Yeah, well, stigma is real.

**[00:34:39.070] - Lucas**

Yeah.

**[00:34:41.440] - Shirlene**

People have opinions and people feel like, you know, hey, I don't have to deal with you, you know. And if they don't want to deal with you, they don't have to. They either going to embrace you and your disease or they not.

**[00:34:54.680] - Lucas**

Well, like you said it before, it's like, if you don't want to deal with me, then good to know. You know, good to know you and bye bye. Also, you know.

**[00:35:02.040] - Shirlene**

And for women, you know, in the very beginning, especially when they were doing clinical trials with the medications, they didn't include us. So you know, we were just taking medications. We took it because we had to take it. And this was medications that was made for men. You know, a lot of us, our bodies have deformed into different shapes, the women. You know women, we like our curves. And when we start taking the medications, like, I never had breasts oh-

**[00:35:44.072] - Lucas**

Look at them now.

**[00:35:45.436] - Shirlene**

Yeah, that's from medication. I put on weight. I was never this big till the medication. So the medication sort of kind of changed, but I go with the flow.

**[00:35:44.500] - Lucas**

And so, that was a huge problem with pediatric medication also. I know one of Visual AIDS' members is 24 year old—26 year old woman from Argentina, and she was born with HIV. They would give her adult medication, just smaller amounts. That's crazy. You know, it's like a baby getting, like, adult medication. And I still think that that's what's happening in a lot, of I don't know how it is here, but in countries in like Latin America, they're still giving adult medication, you know. So we need a cure and we need better medication.

**[00:36:27.800] - Shirlene**

Well, we need to put an end to this pandemic. Even when COVID came out, it was devastating. A lot of people were calling me because I'm like the go-to person. And they were saying, well, what is HASA

going to do for us? They're saying that this new pandemic is going to attack people with compromised immune systems. That's us. That's our population. That's me. I have a compromised immune system. I said, well, I don't know, because I didn't hear from them. And that was weird. I sit on this board all this time and no one said, here's some instructions, or here's something to give out with people with compromised immune system, don't go out, PPE, whatever it is that you need to do. We knew absolutely nothing. People with AIDS. Absolutely nothing. But what I did, we had just gotten a grant and I spoke to Visual AIDS and I said, listen, a lot of people are stuck in their houses, they're afraid to open the door, they're afraid to come out. Is it okay if I go shopping and I go bring it to them? Esther agreed. And I went, I rented a van, and I went shopping and I got donations from different bodegas and different stores that just gave away food and gave away stuff.

**[00:37:45.740] - Shirlene**

And I loaded up the van, I went through all five boroughs, dropping off food, toilet paper, paper towels, hand sanitizer, everything that they needed to their doors. And the look that I saw in their face just made me want to break. Because one guy is on the other side of the door and he's saying, well, I can't open the door. And I said, I'm going to give it to you. I need you to just open the door so I can give you the package. And he wouldn't come out. So I'll leave it there and he says, but I can't open the door. I said, I can't get it inside if you don't open the door. That's how afraid he was. That he didn't want to open the door, period. So as I'm moving around, everybody thought the same. People with HIV / AIDS was living in fear, because we thought with our compromised immune system, we breathe in this so-called airborne disease, that we was just going to immediately die. So they were hiding, and it was so scary to see them hiding. When I got to Queens and I knocked on the door and said, listen, hi, it's Shirlene, I'm here.

**[00:38:45.150] - Shirlene**

I got your bag. You can come outside and—no, I can't come out. It was that much fear. And then my best friend died. And I said, you know what, it's time for me to go in. Because I just wasn't afraid for some reason. I'm going to be honest with you, I didn't get afraid of COVID I was just like, I already have a disease, and I've been through all these other diseases.

**[00:39:06.280] - Lucas**

I mean, you've been so close to dying.

**[00:39:07.700] - Shirlene**

And I said, if it's going to do what it's got to do, it's going to do what it's got to do anyway, so just go out and try to help. So I went through all the five boroughs that I helped out. Up until my friend died I spoke to him on the phone, 4 hours later he was dead. And then I was like, I can't do this anymore. Maybe I better go inside. And then it scared me once he died, and then it scared me. I went in the house. But having two pandemics in a lifetime is pretty spooky to live with, right?



**[00:39:35.630] - Lucas**

It's spooky. And I wonder if you experience something similar, I, besides being terrified, part of me was very angry also, because here we are, like, suddenly this pandemic affects "everybody." It affects straight people, white people, rich people. So suddenly the world seems so mobilized to find a cure or a vaccine really fast in a year. It's amazing what in a year was done. But when AIDS happen, zero, nada, shit about it, right? It affects drug addicts, homosexuals, drug users, and blacks.

**[00:40:32.072] - Shirlene**

Right. So who cares?

**[00:40:34.247] - Lucas**

So who cares? It's like, let them die. So it brought so much anger, that I realized. I didn't realize how much anger I had inside until the pandemic happened. The second pandemic. I say, wow, I have some anger issues that I haven't resolved. It was like trauma that kept coming back. And then also, I remember it brought memories from, I was afraid of AIDS before I got it, right. Because I was gay, it was a gay cancer, so I knew that I could get it, and I forgot about it, but I kept always looking for signs of it. If I had a bruise in my leg, I thought, I have kaposi.

**[00:41:08.300] - Lucas**

If I couldn't breathe, if I had a cold, it's like, oh, I have pneumonia. And this pandemic was the same thing. I felt I was looking for signs that I caught it all the time and it became like a manic thing. You know, it's amazing that you were out there.

**[00:41:30.020] - Shirlene**

Yeah. The life expectancy of HIV / AIDS and of COVID was like, there was none. Somebody is trying to get rid of us. We just didn't know what it was because where did it just come from? You know just one day we're walking and smiling and going to work. The next day we got our mask and can't go out. And we're New Yorkers and we're used to going out every day. And the whole New York City was shut down and no one couldn't go anywhere. And like I said, people with compromised immune system, I have AIDS and I have five types of cancers and if that ain't compromised, I don't know what is. And you want me to walk out this door and do what? And go bump into something that I can't even see or stand next to somebody? I don't know what I'm supposed to do here. And since there was no instructions and then Cuomo came in with his line, the mayor came in with his line, center disease came in with their line and we don't know what to believe, because if you guys know something, say something. Where did this come from? Don't put nothing out here that's airborne that we have to deal with.

**[00:42:40.750] - Shirlene**

We're already battling enough. We had to learn to live with AIDS. Now we have to learn to live with COVID. What else is there out there? How much more can we take? Our bodies can take. My body has gone through enough. I've had 47 surgeries already in 26 years.

**[00:42:58.400] - Lucas**

Holy shit.

**[00:42:59.340] - Shirlene**

It's gone through enough. So whatever happens at this point, I'm okay with it. I'm really okay with it. But the importance of my mission today, is to try to keep everybody safe, bring everybody to a safe mental state of mind, to support themselves and let them know that they're not alone. You know you're not alone and there's a lot of us out here still struggling with HIV, still struggling with housing, health care. We're here. We're here for you. You know. And to just try to, you know, find something to hold on to, like I did. I had to find something to hold on to in order for me to pick myself up and say, I want to live now after they decided that I was going to die in two weeks, that was their decision. It's 26 years later.

**[00:43:49.910] - Lucas**

But do you have other children?

**[00:43:57.860] - Shirlene**

Yes. My daughter, my first child, my daughter, she's 40, and she will be 41 this year. And she's good. You know, I educated her very well. She was devastated when her brother died, of course. And when she saw me in the hospital, laying in the bed, just about this big, thin, pale, she screamed a scream I never heard before. I told her, get her out of here. I don't want her to see this. I want that to be her last memory of me when they thought I was going to die. And now, you know, we're good. I have my grandkids today. I have two grandkids. My daughter graduated. My granddaughter is eleven. My grandson is 15. And who would have thought I'd have made it here this far to see this happen?

**[00:44:43.220] - Lucas**

Amazing.

**[00:44:43.970] - Shirlene**

So I'm happy that there was growth. HIV / AIDS taught me a lot. It taught me how to live. It taught me things not to take for granted. It taught me a lot. It also taught me a lot about politics and my culture. That

you know, black people treated a certain way in this country, and it just is what it is. And we have to fight for everything-

**[00:45:22.034] - Lucas**

But it shouldn't be, thats-

**[00:45:24.044] - Shirlene**

We have to fight for the right to vote. We had to fight for women's rights. We got to fight for HIV. We got to fight for everything. It's like, it's a constant battle. So for me, I always got my gloves on. I'm always ready. Let's go. Who we got to fight now? I don't care what it is, who it is, what are we fighting for? Housing, health care? What? Homeless? What are we fighting for? We got to fight. We got to keep the fight up, put up a good fight. Keep it going. Stay strong. Don't lose your power to anyone.

**[00:45:37.220] - Lucas**

This is a question that I always ask myself, and I'll ask it of you, and then I'll answer for myself. But what do you think HIV taught you the most?

**[00:45:50.760] - Shirlene**

Taught me the most ... taught me the most about my body. I didn't know nothing about biology and my body, different organs, and what can infect them, and I didn't know any of that. I know now. I'm almost a scientist myself now because I got in, I got the books, I got the CDs. Now you know about protease and protease inhibitors, transcriptors, all these different things, words that you never even heard before. It taught you a lot about medicine because you have to pick all of that up in order to move forward to keep yourself alive.

**[00:46:22.070] - Lucas**

You have to be informed.

**[00:46:23.030] - Shirlene**

So you got to learn about your body, what works and what doesn't work in your body, because your body is different from everybody else's. Then you got to learn about these medications, what does what side effects, everything. If you don't know all of that, you're not living with HIV. You're practically sick all the time. And when I was really sick, so I know I had to go through all those motions to get myself well, get on my feet, be able to take two steps. So I went through all of that. Let me read this. What does this medication do? What does this medication do? Is this going to help me? What does my T cells look like? You had to be able to read your own labs. Hemoglobin, your sugar, your high blood pressure, your low blood pressure, all these things. You have to know all this stuff.

**[00:47:05.040] - Lucas**

Sometimes you get an abbreviation. You don't know what it is, you have to look it up, and see what it is.

**[00:47:08.880] - Shirlene**

And when you leave the doctor, because he knows all that stuff, you're alone. Ain't nobody there to take care of you but you. Ain't no phone calls, hey, doctor, what is this? Or, here's a scratch on my arm. No, you figure it out. Get your pamphlets, get your books. And I was invited to the CDC, I think, when did we go? Was it in 2005? I think it was in 2005 to the Center of Disease Control. And I'd ask my doctor, what should I look for when I go there? And he said, look in the labs. And look and see. I got to look through all the telescopes. You get to see all these different diseases that's on the planet, how they working under the telescope. And it's just—that was a scary thing for me, because this thing existed, is nothing to kill that underneath that telescope. It can't die? So HIV can't die? Nothing can kill it? That's weird. When you go and look under the telescope and there's nothing to kill it.

**[00:48:05.090] - Lucas**

It hides in your body. Like, even with the medicines, it's just still there.

**[00:48:09.810] - Shirlene**

It's pretty scary.

**[00:48:10.650] - Lucas**

That's what people don't get. It's like, oh, I take a pill and it's gone. No, it's not gone. It's just hiding somewhere, it's there. The moment you stop taking the medicine, it just comes out, you know.

**[00:48:21.240] - Shirlene**

Yeah. What did you learn from HIV?

**[00:48:23.040] - Lucas**

I think I learned to take control. You know, to take control? Yes. I have an amazing doctor who I've been seeing also for 25 years. But just like you, like to learn to read the lab work, but also to take control of my whole life in general, you know. Life is not forever. AIDS happened, but something else could happen. And how do I want to conduct myself? You know. With dignity, with pride? Not that other people tell me that I'm less because I have HIV and to make decisions, make decisions that are important, you know, about my life. And empathy, taught me a lot of empathy. Not just for other people living with AIDS, HIV / AIDS, but like, to everybody. Everybody, you don't know what shit people are going through because HIV, nobody I mean, if everybody had HIV would turn blue. You'd be surprised how many of us are there.

**[00:49:38.670] - Shirlene**

Right?

**[00:49:39.840] - Lucas**

So you just don't know what people are going through. So when somebody gives me attitude on the street or something, or I feel really like, I try not to judge so much. You know, they are going through a rough day. This is on them, not on me, you know. That's kind of what it taught me, I think.

**[00:50:04.090] - Shirlene**

Yeah. It taught me to make better choices, especially in the bedroom, the dating game. You don't want to reiterate, go and get into bed with another man and catch another type, another strain of HIV, especially after you done got it under control. You're undetectable. I've been undetectable for at least 15 years now, and better once I got on track. I've been undetectable, but...

**[00:50:41.150] - Lucas**

Have you ever had a hiccup? Have you ever had a virus hiccup? You know what that is?

**[00:50:49.076] - Shirlene**

No, what is it?

**[00:50:50.564] - Lucas**

It's like when I, because I get my lab work every three to four months, and I've been undetectable also for many years. But one time suddenly I was detectable.

**[00:50:57.710] - Shirlene**

Oh, the glitch you talking about, yeah.

**[00:50:59.080] - Lucas**

Yeah. Glitch not a hiccup.

**[00:51:01.340] - Shirlene**

You get a glitch. Yeah, that happens. Periodically. It could have been at some point you just got sick for a minute. Like if you get a cold and it'll just roll through, that's why they tell you, don't test while you got cold. Don't take your lab once when you got a cold because it's going to come back with the glitch in it.

Oh, you're not undetectable. So if I'm sick, I usually tell my doctor, say, do the labs the next time, don't do them this time. So, you know, I had to learn all that. That's a learning process as well. But the dating game got hard because everybody you meet, for me, it's like, listen, I want to let you know before we go any further, this is something that I'm dealing with, and I want it to be your choice. I'm undetectable, untransmittable, and of course we're still going to use condom, condom use is important, but it's up to you whether you decide. And those type of conversations can be a downer, if you know what I mean, because you know, you all passionate and lovey dovey and you got to stop. Wait! Yeah, put the brakes on.

**[00:52:02.410] - Shirlene**

Just stop and have a conversation before you do this. It may put a damper in moving forward or just end it at all. I had met a guy when he was taking me back and forth on the Ambulette. I think I mentioned this to Visual AIDS before. And he kept coming to get me. He would make sure he picked me up. I was on his roster. And every time I would get in the van, he would play Al Green, Barry White, all that. And I knew, you know when someone's coming on to you. And we kept going out, going out. He kept taking me back and forth. He finally asked me out. He was an Italian guy. And we went out to Italian Restaurant, had a really good time, and he asked me what was wrong with me. So I told him, and the next time the ambulance come, I was waiting for him to come and get me. He didn't come in, so I never seen him again. But I told him, at least I didn't do what someone did to me, you know, which a lot of people did back in the 80s and 90s even 2000s. Even now, some people are not disclosing.

**[00:53:04.700] - Shirlene**

They're still sleeping with other people without telling. And I think that's ridiculous.

**[00:53:08.480] - Lucas**

Oh, the importance of disclosing is so ... I mean so important, it's key you know, and it's also something that you learn from, also, you learn about, learn about yourself and you learn about other people. And I used to take it so personally, the rejection after disclosure. And then one day something clicked, and I was like, no, this is not about me. You know it's like this is about that person, you know, their fears, their inability to cope. And it's on them, you know, it's not on you.

**[00:53:46.260] - Shirlene**

Yeah, the rejection didn't—I didn't worry about rejection. Yeah. It just didn't carry over, you know, rejection. I was just like, I'm talking, we're having a good conversation where-

**[00:54:13.325] - Lucas**

You're sharing your life.

**[00:54:14.056] - Shirlene**

I'm sharing my life with you. You either want to share it or you don't. If you want to go, bye, because I was spared, I was given another 24 hours. I was given another 20 something years that I wasn't expected to have. So I'm here and I'm going to live every day to the fullest, and I'm enjoying it. I'm not going to let somebody with stigma, hate, or shame ruin my day. Well, I made it to another day that HIV / AIDS didn't take me out because it could have took me a very long time ago and it didn't. So it's wonderful and it's such a joy to be here that I don't even allow those things in my space. They don't come in, and I just keep going. If you were like, what are you doing today? Well, I'm going here. Like, I took a moment to go down to Puerto Rico with Wanda Hernandez, the lady who invited me to the Love Positive Women group, because she moved to Puerto Rico, and we had such a ball down there, and immediately I was looking for the AIDS population.

**[00:54:59.600] - Shirlene**

You know, that's me. Always keeping my organizer's hat on. Where are they? How many people on the island have HIV and AIDS, type of housing and stuff that they're getting? And she's doing very well down there. She's doing very well.

**[00:55:11.640] - Lucas**

That's great.

**[00:55:14.300] - Shirlene**

You know, If this is so in your soul already, you know, when you wake up in the morning and you move with it, like you said, it's your companion, right? And you take it in, with you where you go, and you just go with the flow. You just keep going. You know, you have to be unstoppable now. You have to be unstoppable. That's the only choice. Don't allow AIDS to stop you. And I tell this to all the women in the group, because a lot of them look at me as a leader, because I'm a leader amongst women living with HIV and AIDS. They're like, how do you do it? Self care, wellness, self taught empowerment, pride. Don't allow nobody to stop you. AIDS does not define you.

**[00:55:58.870] - Lucas**

Absolutely not.

**[00:55:59.830] - Shirlene**

You wasn't born with it. It does not define you. Define you. And that's why I always say, give me an affirmation.

**[00:56:06.980] - Lucas**

But that's also the importance of disclosure, because not only when you disclose, you're not defining yourself, but it's a test for the other person, I think also. Because you're not able to cope with me being HIV. Like, what else are you not able to cope with, you know, in life? You know, and so I think it's just so much more about the other person than yourself. When you disclose and when they embrace you, it says something about them also.

**[00:56:37.520] - Shirlene**

And some people are just not going to embrace you. Like, I worked in the HIV / AIDS field for 20 years, so I decided, I'm not going to work in the HIV / AIDS no more. I'm just going to get a regular job. So I went to work with the Department of City Administrative Services. One of the girls there, I don't know, maybe Facebook or something, may have told her that I have AIDS. She went and sends a text out to everybody.

**[00:57:02.410] - Lucas**

This is what year. Excuse me.

**[00:57:04.090] - Shirlene**

This just happened. 2018.

**[00:57:05.720] - Lucas**

Oh, my God.

**[00:57:06.620] - Shirlene**

And I went to an equal opportunity for employment. I told them, because when I came back in, somebody had cut my boots, cut a hole in my boots. And then they told me I couldn't hang my coat where everybody else hang their coat. So I just carried my coat with me.

**[00:57:24.150] - Lucas**

2018, like three years ago? Yeah, four years ago.

**[00:57:27.480] - Shirlene**

I was working at 210 Joralemon Street, and they took my rain boots. They cut them, and they told me I couldn't hang my coat up where everybody else hanging they coat up. And this was after I had already got in the door. I was already in, working. So then I said, you know what, I'm not going to fight with these people here. So I relocated to a location which was out in Long Island City, training the firemen and the



same thing, one of the women—because I'm a leader—so I act like a leader and I take charge I do my job very well, very thorough, I'm professional. And you come in, first you got the woman hate, without the HIV. She didn't know I was HIV, but she found that ammunition on me because she went on social media. Because if I tell all these people in there that she got AIDS, maybe they'll fire her. Get her out of here. That was her motto. And guess what? And I did get fired. I'm not there anymore. So it remind me of Tom Hanks. Hey, *Philadelphia Story*. You get fired for what? What are you fired for?

**[00:58:26.490] - Shirlene**

I didn't do anything wrong. Leave my house. 05:00 every morning. I would get to work by seven in Long Island City. I do my job thoroughly. Come in. I meet and greet all the employees, taking the fireman, come on and right this way, sir. Why do you want to be a fireman? Right this way, sir. Right this way, sir. I'm fired from that job. Right now we're sitting in litigation with the equal opportunity in the Human Rights Commission today, right now, to get my job back. So when I went to apply for jobs outside of the HIV / AIDS world, it's a struggle because people are going to try to throw you under the bus. Oh, she got AIDS, she shouldn't be here. Don't let her go in the bathrooms with us. Don't hang a coat, don't... you know, destroy her. Get her out of here. First of all, I'm not afraid of you.

**[00:59:14.970] - Lucas**

But it's outstanding the ignorance...

**[00:59:19.700] - Shirlene**

But the fact that the bosses on the job allowed this to happen today, they did not step up and say, this woman is very thorough. If we evaluate her, she's on time every day—I'm the first one there. She's thorough. She's encouraging all these new firemen to become firemen. They were so great. They would thank me at the end when they passed the test. Thank you so much for your encouragement. I did everything I was supposed to do right? And they still fired me. For what? What did I do?

**[01:00:00.410] - Lucas**

Unbelievable.

**[01:00:01.240] - Shirlene**

So right now we're still with the Human Rights Commission for discrimination. Then they tried to say I was selling. Selling what? AIDS? What am I selling? So they just made up stuff and the fact that the bosses that ran the operation didn't step up and say, that lady, she didn't do that. No, that's a lie. So the EEO made it up. His wife and him, they're have marriage, couple. So I'm battling the entire D guys right now. It's been to, look, 2018 to now, 2022. We're still stuck. So the pandemic came through and we got stuck even more. So it's just stuck here. So I'm unemployed, but I haven't given up. I'm still fighting. The Woman Empowerment Art Therapy Group is once a month, so that's still operating properly. And I'm so proud of all the women. We just went through Women's History Month. We took all the ladies out to dinner.

**[01:01:04.310] - Lucas**

That's great?

**[01:01:05.610] - Shirlene**

So it's just been fabulous. You know you have your ups and your downs with HIV. It depends on how you see life, whether you're going to take it. I'm not taking AIDS on the downside, it's always got to go up. How about you?

**[01:01:25.730] - Lucas**

I have, you know, I have no struggles in that regards because fortunately, I'm able to live from my work right now, so, like, selling my work and taking photographs for magazines. But I wonder, you know, if I had been so public about my status, because I don't hide it, but I'm not a public figure about it.

**[01:02:03.034] - Shirlene**

Right, you aren't advertising either.

**[01:02:11.064] - Lucas**

But I wonder what effect it would have in my life, in my day to day life, you know. And that's part of the reason why I wanted to join Visual AIDS. Part of the reason why I want to be in this conversation is to be more public about it. I think we all have to show our faces and in order for, AIDS is not over, but the stigma is definitely not over.

**[01:02:23.240] - Shirlene**

Yeah, absolutely.

**[01:02:23.940] - Lucas**

I mean, what's happened to you with the labor issue, with your job, is—if there was no stigma, that person would have been laughed at, you know, for trying to get you fired for having AIDS. You know, they would have been fired, you know. So I think the more we come out of the woods, the more we talked about these things. That's what I want to do. The more out there I am, the less stigma there will be, you know. I cannot find a cure for it, you know, but what can I do that helps, you know? It's just showing up, I guess ... just showing up.

**[01:03:07.550] - Shirlene**

Yeah, just being a part of, you know, the advocacy and all the activism that's been going on with HIV and AIDS. Like I mentioned to you earlier, my first rodeo was with ACT UP in Bangkok, Thailand

**[01:03:33.XXX] - Lucas**

Russian.

**[01:03:33.XXX] - Shirlene**

And I had no idea what they were doing. And they just were jumping on chairs, "apartheid" and screaming, and I didn't know that this is what we came for. And...

**[01:03:32.330] - Lucas**

You were doing an action?

**[01:03:33.920] - Shirlene**

Yeah, we were doing an action, and we trashed Pfizer's booth and we spread Jello like blood all over his booth. And that was my first action. My first action was incredible. It was incredible and scary at the same time because first I didn't know what we were doing. And then when I realized what we were doing, I finally figured out what we're doing. I was like, wow, this is great. Yay. "No justice! No justice!" I'm ready now 'cause I didn't know that...

**[01:04:05.560] - Lucas**

But also, you're in a foreign country as well so

**[01:04:07.970] - Shirlene**

And we're in a foreign country.

**[01:04:09.590] - Lucas**

Which, you have no idea.

**[01:04:10.970] - Shirlene**

Nothing. What politics look like.

**[01:04:13.660] - Lucas**

Exactly.

**[01:04:14.230] - Shirlene**

Democracy.

**[01:04:15.930] - Lucas**

Yeah. My first action was when I was in college in Rhode Island, but I was not a citizen yet. And there was so much stigma about people with AIDS because we were homosexuals, drug users. right? So my first actions, I was in the periphery, I was like a support. I would accompany people. So I accompanied people that went to the Providence City Hall.

**[01:04:45.830] - Shirlene**

Mhm.

**[01:04:46.730] - Lucas**

And they locked themselves in the governor's office. So I would just be outside with signs and yelling. But I wouldn't actually take part of the action because I was really afraid that if the cops, that if I would be arrested, that then they would not give me the green card. They would revoke the green card. They would send me packing. So I would do a lot of screaming and yelling, but I wouldn't... but always a little bit on the outside until I got my citizenship, yeah.

**[01:05:17.270] - Shirlene**

Right.

**[01:05:17.740] - Lucas**

Then I was like, okay, now they can send me to jail, but they won't send me to Argentina. You know. Do... there's not that many actions anymore. And I think surrounding AIDS, HIV / AIDS is there?

**[01:05:38.470] - Shirlene**

They're having actions, but not as much as they used to. I can recall when Dennis de Leon, who was the executive director of Latino Commission on AIDS, got the first funeral for a person living with HIV and AIDS. Of course, the incredible Charles King. The incredible Gina Kotropi from Bailey House. All these different people I worked with around of executive directors, where we were out there fiercely. Just every week, we're up in Albany or we're down in DC. So we doing, either we're working on local bills, or state

bills, or federal bills. We were always there, and it was every week consistently. And then you had to build advocacy amongst the community and get the people that were directly affected to come out. So all of that organizing, and this is all the stuff that I've done. I'm coming in. You got a problem, you want to talk about it or you want to be about it? Let's go. I'm going to get you on the steps of City Hall tomorrow. You're going to speak to our mayor. You're going to speak to community. This needs to be exposed. If you have a problem and no one knows about it, we can't help you.

**[01:06:45.060] - Shirlene**

We need you to get out here and show what's going on. And I was able to get everybody that I organized, was able to speak, put in public, every last one of them. I will put them in front of a mic. Let's do this. This is what needs to be done. We cannot fix this problem by sitting back. Our voices need to be heard. You got to have a voice here. And we would bring them out, and they would just speak. City Hall. Bus loads going to DC. I remember during the Democrat national convention, the Center of Community and Change had called me, and he said, we are going to Columbia, South Carolina.

**[01:07:21.580] - Lucas**

Which year was this one?

**[01:07:22.840] - Shirlene**

I think this was 2005 as well, something like that. And Dean shopped and carried everybody was there, and I filled five bus loads of New Yorkers. Five. They said they were going to give us one. They said, how many buses can you fill? I said, well, how many you got? And I filled five buses and still had people over. We had to send to other places to get on their bus, because I had overwhelmingly filled all these buses. And when we got down to Columbia, South Carolina, of course, you saw the confederate flags, and we were marching to the town hall. "War. What is it good for? Absolutely nothing." Just marching, trying to go. "When people with AIDS are under attack, what do we do? Act up, fight back!" All the little chants that were going on, and finally got to the town hall where they were, and we saw Sharpton, and they were asking different questions about, you know, people with AIDS. And basically, I think that time was the hopper spot, when they swapped a few million dollars to pay the case workers from our housing, and we were upset about it. Find your own pot of money.

**[01:08:33.580] - Shirlene**

Leave the money for the housing alone. You know. It's just crazy. So the politics that you have going on with this and the places we had to go, the things we had to do, the gender bill took forever, you know. Then Cuomo signed on gay marriage. The gender bill took, what was that, 13 years, I think, because I was running the gender bill for Charles King out of Housing Works, East New York. It was just crazy. Going up every Tuesday, meeting with 200 senators, and they all were against it. "No, we don't want gay men in the bathroom with our daughters" and all these different things that were going on. And finally it

passed. I mean, we're just human beings. We just want to live like everybody else. Someone has to hear our voice. Somebody has to pay attention. Somebody has to be held accountable for this. So we fought and fought and fought. Now that a lot of those things have come true to life, I guess people are lapsing on their advocacy and their activism. "Hey, we got this, so we can" no, there's no room for that. AIDS is not over. It's not over. And the only way to make it, is to continue to get out there on the front lines and let them know we're ready for this cure.

**[01:09:49.570] - Shirlene**

Because what I see is like, they're just waiting for us to die out, generation, after generation to die out of it, and then that's how it's going to be over. Why can't you produce a cure like you said, with the COVID pandemic? They came out with a vaccination so quick, go get your shot. Like, where'd that come from? So quick. We didn't know what was in it, and everybody was so skeptical. Some people are still skeptical, won't take it. I got my two shots, I went and took 'em, and I felt because I had to.

**[01:10:18.110] - Lucas**

Yeah, if there's a medicine for it, give it to me. You know it's like...

**[01:10:23.290] - Shirlene**

We weren't sure what it was. You just made this up. And once you stick someone to stick it in their arm.

**[01:10:27.010] - Lucas**

Yeah. Well, I would, but that's having gone through HIV / AIDS, knowing what not having medicine did to people.

**[01:10:40.690] - Shirlene**

Yeah.

**[01:10:46.530] - Lucas**

Yeah, I was not suspicious of the drugs at all because I was so angry, but also because I realized, oh, no, this is not a gay drug user disease so of course they're going to give some ... nothing they're not going to put out something out there that is a threat. A physical threat. But I understand people being suspicious, but I'd rather take the risk, always taking medicine.

**[01:11:18.160] - Shirlene**

Any disease is a danger to mankind. And having to learn to live with it, like, we had to learn to live with HIV and AIDS. And every day we wake up, it's difficult. Because you don't know whether you're going to

wake up sick or not. That's the whole thing. So some days you can wake up and you're just fine, feeling like superwoman, and then the next day you'd be, oh, my God, it's so much pain, and you still have to function. To me, I'm used to pain, especially from the very beginning, from the diagnosis, so I could still work in pain and sort of kind of ignore it because it's been there so long. But the HIV / AIDS fight is far from over.

**[01:12:03.660] - Lucas**

Well, also when people say, oh, it's just a cold, it's like, well, not if you have HIV / AIDS, you know, or if you have other underlying conditions. It's not just a cold. You know, it's like anything is more dangerous and more of a risk when you live with—excuse me—a chronic disease. That's why people are saying, like, oh, yeah, the Omicron, it's just like a cold. It's like, hey, you don't know. You don't know what's going to happen in two years after you had Omicron now. But I'm living with HIV. You know, it's not just the cold. Don't you dare say it's just the cold. Take it, you know, take it seriously. And that's why I think it's so important for people to mask, not just for themselves, but for other people. You don't know who's in front of you. Somebody may not know that Shirlene is like an HIV cancer survivor and, you know, they're here without a mask. Blabbering. Blabbering. Blabbering. In a public space. It's disrespectful. It's ... disregarding.

**[01:13:19.790] - Shirlene**

During the pandemic, what we did with the Woman Empowerment Art Therapy, we transferred over to Zoom like everybody else did, do everything. Zoom the meetings were fantastic.

**[01:13:30.970] - Lucas**

I was going to ask, how was that? How did that work?

**[01:13:33.260] - Shirlene**

Everybody got on. And what we decided to do was, since we couldn't do an actual art project, that we would get art kits and mail them out to all the women and that they can do their art in the spare time that they were doing nothing because the city was locked down, and then show them off on Zoom. So that turned out really well. And then we had, of course, Blake Paskal, our Art Educator, he would show slides of different artists and their works, and it was incredible. And it was like once a month, every time we came on, folks, we had the Ukraine on, we had Palm Spring, California, Florida, now North Carolina. People just was coming into ... the woman empowerment piece just escalated when we thought that, oh, this is it, you know, we started this woman empowerment, now here comes this pandemic. It's going to shut us down. Instead, it uplifted us. It got better, it grew. It's much stronger, it's more powerful. And we're in our fifth year, and I'm so grateful that Visual AIDS decided to take this on as a project of them and make this a whole, and give women a space where they can come and they can heal, because there's not a lot of places for women to come and heal.

**[01:14:52.210] - Shirlene**

And I structured this group around what everybody else is not doing, we're doing. Because in the past, when you went to groups, they had so much of this in one group, so much of it. So you grouped out, right? And you just not going to groups anymore. You done went to groups of five, six, seven. Some people go to group ten years, pizza, Metrocard, same old conversation. We don't, that's not us. We're different. We frame you, we give you a voice, we bring the creativity out of you, and we allow you to heal all at the same time. We do meditation, we do dancing, all kinds of things that the women can come to a space and say, wow, I feel good when I leave this group. We had one woman, she said she didn't get along, her husband doesn't get along. Now he loves her even more that she started going to the groups. They're talking now. You get in a marriage, relationship, it goes, they're talking again. And she said that's because now she sees things different. She's directed her anger and her attitude in different ways since she's coming to the Woman Empowerment Group, and her and her companion is speaking again, and he's so happy.

**[01:16:10.890] - Shirlene**

He tells her every month, get out.

**[01:16:13.210] - Lucas**

How long are the meetings take? Two hours.

**[01:16:14.960] - Shirlene**

Their meetings are two hours. And they're so much fun. They're so entertaining.

**[01:16:19.130] - Lucas**

It's so amazing. two hours, once a month. two hours. How it can affect someone's life.

**[01:16:24.500] - Shirlene**

It can affect someone's life.

**[01:16:25.570] - Lucas**

Imagine if, like, everybody could get something like that, right?

**[01:16:31.330] - Shirlene**

Yeah, that would be incredible.



**[01:16:32.600] - Lucas**

It's so healing.

**[01:16:34.450] - Shirlene**

Are we good?

**[01:16:35.680] - Constantine**

Lucas, I wonder if we could talk, if you could spend some time talking about your work.

**[01:16:41.910] - Lucas**

My work? Sure. Yeah yeah.

**[01:16:44.790] - Shirlene**

Yeah, please.

**[01:16:46.950] - Constantine**

Everything is great. All of our like moving things around is just to get you even better.

**[01:16:52.250] - Shirlene**

I was worried about me being dry. I had to take pills this morning. It's so dry. I'm trying to talk.

**[01:16:55.220] - Lucas**

You want some water? I was going to.

**[01:17:00.250] - Shirlene**

Thanks.

**[01:17:02.750] - Lucas**

No, I'm okay. Because otherwise I'm going to want to go to the bathroom. Are we still rolling?

**[01:17:08.330] - Shirlene**

Yeah.

**[01:17:09.060] - Lucas**

Okay. That's something that, like you know, when you talk about work, the Woman Empowerment Group, as healing, and like the making of art as healing, that's how I view my own art practice. And all the work that you see here.

**[01:17:42.320] - Shirlene**

Yeah, it's amazing. I love it.

**[01:17:44.043] - Lucas**

It's very personal, but like for me, it's very important that the work is personal. It's about me, but that you can see yourself in it. So it's not just me about me.

**[01:17:38.580] - Shirlene**

Right.

**[01:17:39.130] - Lucas**

But all these paintings, for instance, are like, it's almost like ... these paintings in particular, gives you a view. It could be something that you're looking outside into space, but also you're looking inside into your body. So it could be like a cellular structure or an intergalactic view of something.

**[01:18:01.020] - Shirlene**

Okay. What inspired you to...

**[01:18:04.840] - Lucas**

I think I'm always inspired by my own personal life. So this inspired me talking about healing. The ones with the dots are about chakras, the healing chakras in yoga. But also the dots become like petri dishes. Because you know when you were talking about how HIV taught you to look at your numbers, inform yourself about medicine? Well, I think we, people living with HIV, AIDS, we're so hyper aware of our bodies all the time. If you ask Joe Doe across the street if he knows what his numbers are, he wouldn't know shit. You know what I mean? We are so aware of it. So for me, this is like also these chakras are also like petri dishes. It's like looking at my blood, like my cells or being always aware of you wake up in the morning and you are aware of your body all the time.

**[01:19:08.120] - Shirlene**

Right.

**[01:19:09.330] - Lucas**

So this work reflects a little bit on that.

**[01:19:12.630] - Shirlene**

That's great. That's perfect.

**[01:19:15.270] - Lucas**

But I also want you to look at it and see some whatever you want to see.

**[01:19:18.140] - Shirlene**

Yeah. You get exactly what you're describing. You can see internal and external. You can see exactly what you're describing. And that's amazing that you were able to capture that like that.

**[01:19:28.320] - Lucas**

Oh, thank you.

**[01:19:29.580] - Shirlene**

You're artists. Wow. We got to come and see your art to bring the ladies.

**[01:19:34.590] - Lucas**

Yes. Oh, my God. That would be great. You could—I can leave the room, but you could hold one of the empowerment groups here and like make art here.

**[01:19:44.140] - Shirlene**

When did you become an artist?

**[01:19:47.250] - Lucas**

You know I fought being an artist for a long time, because being an immigrant, my parents being immigrants, I always thought that I needed to, and if they were going to spend the money to send me to college, that I needed to do something “practical”.

**[01:20:03.310] - Shirlene**

Okay.

**[01:20:04.120] - Lucas**

But I was always artistic. So, I studied industrial design. I worked in an architecture firm, but always art. Fine arts always called me. So on the side I was always making art. And finally, around the time that I tested positive, I had to make a change. I have to find purpose in life and do what really makes me happy and what's really or what's true to myself. So a couple of years after testing positive, I moved to Los Angeles and I had a whole slew of jobs to survive. But I really dedicated myself to making art while I was doing all of those things. So about 25 years.

**[01:20:59.160] - Shirlene**

25 years?

**[01:21:00.070] - Lucas**

25 years, yeah.

**[01:21:01.540] - Shirlene**

And how did HIV and AIDS reflect on your art?

**[01:21:06.650] - Lucas**

Well, like what I said, this in particular is very much about looking at my own body, like the awareness of my body. But there's other works that are about ... “places” a lot of works that I've done are about glory holes. Do you know what a glory hole is?

**[01:21:28.800] - Shirlene**

No.

**[01:21:29.520] - Lucas**

Glory hole, it's a hole in the wall, places where people, men, put their penises. It's like, so a lot of the works that I've done in the past is about places where people have anonymous sex and using that as a starting point to become a more poetic thing and, so that's because you know, that's how I caught HIV, you know, from having well, from having sex and from having anonymous sex. So, that it was important for me to include that in the work at times, you know. But it's in many ways the work I'm doing now. Also these paintings here are large paintings. I take a Polaroid, during the pandemic when there were so many death around us. I started, and I didn't feel comfortable going out too much. I would walk here, buy flowers and take Polaroids of these flowers as they were dying. So the flowers became kind of my own stand-in for myself, for dying bodies. But I was finding beauty in the dying flowers.

**[01:22:54.950] - Shirlene**

That's interesting.

**[01:22:56.990] - Lucas**

And I took all these photographs that were very beautiful, but I would take Polaroids. And the Polaroids that I use have a film that you peel. So with that film I would do transfers. And the transfers are this big. I'll show them to you after this. And there were these very abstract shapes and then I enlarged them and made paintings of them. So these are actually doesn't look like it, but it's a painting of a flower, of a bunch of flowers. And I think that's how I incorporate my HIV / AIDS into the work. That what you look at is not what it seems. Something is like a glory hole, but it's actually an abstract painting that I took a lot of time rendering until it became like a meditative thing. I use my art making as a meditative practice as well. So I meditate a lot when I make my work. So I use making work as a healing process also.

**[01:24:09.650] - Shirlene**

Yeah, that makes sense though. It really does heal. Most of the art that I create, you know, with the women empowerment was about faith. It's about hope, it's about holding on, and it just comes out of you.

**[01:24:20.630] - Lucas**

Yeah. Tell me about that collage.

**[01:24:22.770] - Shirlene**

This collage here was made, we were at Project Recess. It's a project that sort of kind of brings youth and reentry in from prison and they allowed us to use their space. So what we did was we all sat down and we wrote our feelings on paper and we painted it and then we cut them up in little pieces and we had each person go and paste it on the wall.

**[01:24:59.910] - Lucas**

So this is a work that is made by 30 people.

**[01:25:03.660] - Shirlene**

That would have been happy. I think that would have been happy. Different words, but if you cut them up into pieces, right? You cut them up into pieces and then just, somebody put illness. I think that was illness. But once you cut them up into pieces and then just place them in different areas, like if we took that apart and put the words back together like a puzzle. So we just mixed it up and we had everybody go up there and attach something and this is what we came out with and we thought it was fabulous.

**[01:25:36.050] - Lucas**

I think it's great because it's like a communal work actually.

**[01:25:40.050] - Shirlene**

We've done a communal rope as well, with MoCADA. We were at the MoCADA and we've done a communal what do you call a rope. So, yeah, different times we do different projects.

**[01:25:53.810] - Lucas**

It seems like a quilt? In a way. Like the healing power of quilting. Right. It's very ancestral.

**[01:26:00.160] - Shirlene**

We're looking forward to doing the quilt with Dave Harper sometime in the Fall. It was supposed to be-It was pushed back, so we're going to do a piece onto the quilt. That's going to be an extravagant project as well. I've never got to see the quilt up close and personal. I've always wanted to see it. I always wanted to add my son on to it and I never got the opportunity. So I think that we have the opportunity now to work with Dave Harper and work with the quilt in the Fall that we're going to do something incredible to add to the quilt.

**[01:26:33.880] - Lucas**

Are you going to add your son's name?

**[01:26:35.590] - Shirlene**

I definitely, most definitely am. It'd be the first time we get into this quilt. I know this quilt has been around a very long time and it's symbolic to all the losses of people living with HIV and AIDS. And I think it's time

to add more people because more people have died since then. I think it's probably so humongous now. They probably split it up or something.

**[01:27:00.970] - Lucas**

Are you on Instagram?

**[01:27:02.630] - Shirlene**

Yes.

**[01:27:03.230] - Lucas**

Do you follow the AIDS Memorial account? I think that's an amazing account.

**[01:27:07.760] - Shirlene**

Yeah, they have an amazing account. They sent out stuff every day.

**[01:27:10.940] - Lucas**

Have you ever put Keenan in it.

**[01:27:12.830] - Shirlene**

No, I haven't done any of that yet. My social media is not as savvy as others. I mean, I'm not on it that much.

**[01:27:21.960] - Lucas**

Well there's only so much Shirlene can do, you know. You do a lot.

**[01:27:25.970] - Shirlene**

I need my free time sometimes. I said if I stay on social media, social media is addictive as well. You got to remember, that because I know some people that live on Facebook and Instagram with a lot of their work. Me, I just try to keep it neutral. We do have a Woman Empowerment Art Therapy Group page where we post our posters of when we're having our meetings in our group or if there's something fantastic that's coming up. We do have a Woman Empowerment Art Therapy Group page that anybody can join and just get to see our work and stuff like that.

**[01:27:55.920] - Lucas**

But I would love to take you on, like having the Women Empowerment Group come here.

**[01:28:14.XXX] - Shirlene**

Yeah, we would definitely love to come...

**[01:28:15.XXX] - Lucas**

...make something. Or do you show and tell or, you know. I would love that. It would be an honor.

**[01:28:08.370] - Shirlene**

I love your art, though. I really do. Once you explained it, it really does speak volumes. Internal and external. Like you said, it's something that you can't see internal that's traveling through your body, then external. Now you can actually view it. Wow. That could be what's going through my vein, through my blood, through my tissues, through me that I cannot see, but at the same time, it makes you feel whole.

**[01:28:32.540] - Lucas**

Yeah. I'm a strong believer in dualities. We're never just one thing. One thing, like you said, HIV doesn't define you. You're not just HIV or AIDS victim. We're victims, but we're also perpetrators you know. You're a mother, but you're also a daughter. We're always more than one thing. And I think I really tried to explore that in my work. I wanted to be these are paintings, but they're also drawings, but they're also tapestries, and they highlight tapestries. This is an abstract work, but it's an abstract work of something that is actually real. So it's not an abstract work.

**[01:29:17.460] - Shirlene**

Okay.

**[01:29:17.820] - Lucas**

It's a painting of something that it's a figurative work, actually. And, you know, I think people are that way, too. Right. It's like, pretty much every day we are multidimensional. That's the beauty of it.

**[01:29:35.490] - Shirlene**

I think that is definitely the beauty of life.

**[01:29:38.190] - Lucas**

But I love listening to your story, and I've always been inspired by you. You know it's like...



**[01:29:49.410] - Shirlene**

By you as well, because I love art, and we're trying to get the ladies to the next level of art. Blake has been doing an incredible job of teaching the ladies. We've learned watercolors and different things. Like, if you can teach us something, you know, the ladies would love that.

**[01:30:05.750] - Lucas**

I will give you. You know what? I will give away my top secret to your ladies, which I haven't shown anybody, which is how I make all these crazy lines.

**[01:30:19.040] - Shirlene**

Okay, okay.

**[01:30:19.290] - Lucas**

Which is what people wonder about when they see my work. Like all those curly cues.

**[01:30:24.510] - Shirlene**

Yeah, yeah.

**[01:30:29.470] - Lucas**

We'll do that.

**[01:30:30.660] - Shirlene**

Okay, well, I definitely have to put that on the agenda.

**[01:30:33.500] - Lucas**

Well, that's fantastic. I love having a plan of what to do.

**[01:30:37.810] - Shirlene**

Good job. Thank you.

**[01:30:39.410] - Constantine**

I think before we get up close with all your art and stuff. You don't have to answer this if you don't want, but one of the questions on the sheet was, is there a question that you wish someone would ask you? I don't know if there's a question...

**[01:30:57.210] - Shirlene**

If someone would ask me...

**[01:31:01.550] - Lucas**

I had a difficulty answering that question, actually, because I'm always ...I always know that I will wish I would have asked Shirlene another question when this is all over, but I can never know. Like, oh, I wish somebody would ask me this, because yeah, it doesn't work that way, right. It's not a question. Then it's like, is there something that you would like to say about yourself? Then maybe that's a better way to phrase it I think.

**[01:31:39.830] - Shirlene**

Someone had asked me a question, what would you be like if you didn't have AIDS? And I found, like, very intriguing. I was like, wow, I've been HIV-positive for so long, I can't sort of kind of relate to myself when I didn't know I didn't have AIDS or what would I be like? So that was a very powerful question. They asked me, what do you think you would be like if you didn't have AIDS? It's almost impossible to try to find an answer to it because what would I be? I guess I would still be the same person, but without having to monitor the numbers every day, not having to go to the doctors all the time, not having to take the pills all the time, that would be the answer. But other than that, I think basically I would be the same person.

**[01:32:33.020] - Lucas**

But also it's like one of those questions where, like, sure, you can wish all you want, but that would never happen because what happened, happened, right? Yeah. My question is similar to that would be kind of like, do you regret having HIV? Or if you would do it all over again, would you avoid that moment? And again, it's like, damn if you do it, damn if you don't. Because like suppose that I say, oh, yes, I wish I hadn't. Then you leave feeling heavy and like hating yourself at the same time. It's like, I love me. I love who I am. We wouldn't be having this conversation, right.

**[01:33:15.800] - Shirlene**

Would I be an activist? Because I wasn't. Would I be an advocate? Because I wasn't when I didn't have AIDS. So, you know that's that's a question.

**[01:33:25.250] - Lucas**

You would be in an unhappy marriage with somebody that is cheating with man also, you know? But also there would be a lot of things, some things that happen to you that wouldn't happen, but like I don't know, it's like, to me...

**[01:33:42.970] - Shirlene**

So a lot of horrible things and a lot of tragedies I went through with living with AIDS, but then I had some of my best moments as well. Some of my greatest successes came from AIDS. I got awards, so many awards that don't even make no sense. And it's all through AIDS, not through me being me without AIDS. You know what I mean? So, you know, for someone to ask me something like that, I was like, I really don't know how to answer that. It's hard. Because AIDS created a new person. It created a new soul. It created a new mission for me.

**[01:34:19.910] - Lucas**

And who is not to say that that's a person that you were meant to be?

**[01:34:23.900] - Shirlene**

Exactly.

**[01:34:26.810] - Lucas**

I mean, right? Because we are who we are.

**[01:34:31.850] - Shirlene**

You know a lot, some of my friends, mostly everybody that know me, should know that I have AIDS, right? They should know because I don't hide it. I don't go around advertising, but most of them know because I've been on the front page of the Daily News, I've been in POZ ten times already. I've been really been out there, you know, lots of times. New York 1, All the channels, Master Media, press, all that. I've done all that. So most people should know. But those who don't, you know, they may say to me, wow, you're doing really good in life. And I may look at them, how so? I'm looking at them like, how so, you know? I got all these struggles and you don't. My struggles are ten times larger than yours. So what makes you think that I'm living a good life?

**[01:35:25.610] - Lucas**

You know what happens?

**[01:35:26.580] - Shirlene**

Because it appears that way. A lot of people swear all out that I'm the richest person on planet. No, I am not. I am totally unemployed.

**[01:35:34.340] - Lucas**

Yeah.

**[01:35:35.550] - Shirlene**

I just enjoy each day, and it makes it appear as if you have everything and everything's fine, but it's not. I know that, but the world doesn't know that. But everybody's view, everybody's lens is different. She looks nice and clothes, and then she must have money, right? Yeah, she looks healthy. She don't look sick, so she must not be sick. She's always happy, so she must be happy. People just don't know. Like you said, you don't know nobody's struggle behind the scenes.

**[01:36:04.690] - Lucas**

Well, but that's part of the stigma. People think that HIV / AIDS is like decrepitude, sadness, infirmity, you know? That's why what shocks me is when people assume, the first assumption is always that one, doesn't have HIV / AIDS. That's the first assumption because you look good, you look fine. That, to me is always almost shocking because it always puts a responsibility on you to disclose and to correct them, you know. My thing was always when I was even before I tested positive, my thing was assuming that everybody was positive. Did I fuck up and ended up getting HIV? Yes. But I never assumed that somebody wasn't or that couldn't be. Or they look good, they couldn't possibly "have it." So it almost offends me sometimes when people talk, and then they always will say something about HIV or AIDS that is dismissing or diminishing. And I'm like, you ignorant fool, you don't know that I have it, and you're assuming that I don't. And it's always shocking to me.

**[01:37:30.080] - Shirlene**

Well, the conversations are still uncomfortable at the table today as they were years ago, because you just can't be sitting at a restaurant, we're all out having dinner, "hey, oh my God, did you see this HIV / AIDS story today" or something? You just don't do that. It's like still an uncomfortable conversation to put on the table. "Oh, my T cells got high, girl, whaaat I'm good" at the dinner table. It's still the same uncomfortability, it's still the same stigma around speaking HIV / AIDS at the table. So it's like it's still being talked behind closed doors because that's where people feel comfortable. People are not feeling comfortable just to bring it up.

**[01:38:16.050] - Lucas**

And that's the beauty...

**[01:38:18.530] - Shirlene**

That's just where HIV is going today.

**[01:38:21.180] - Lucas**

But that's the beauty of the woman empowerment group and Visual AIDS, that it creates a space. But we can have this conversation...

**[01:38:29.180] - Shirlene**

Over and over again many times as you want.

**[01:38:31.530] - Lucas**

It's just normal.

**[01:38:33.040] - Shirlene**

And it's normal.

**[01:38:35.210] - Lucas**

You know, it's not great I'm HIV or it sucks I'm HIV. It's just is, which is what it should be.

**[01:38:43.710] - Shirlene**

And we need more spaces like that because you still can't go to your family reunion and talk about AIDS or go to your buddy's house, "hey!" There's still not a space for that. Will there ever be? I don't know. Everybody's so uncomfortable with it.

**[01:39:02.260] - Lucas**

I was so happy when my brothers, my brother, I have nieces and nephews now, one is now 18, the other one is seven, the other ones are 15. But when they told me, we're going to have this conversation if it's okay with you, with the kids, to let them know about your status, I was like, Hallelujah, please do, you know. And after they have that conversation, my niece then interviewed me for her high school project and then wanted to get involved with Visual AIDS. I mean, these conversations are so necessary.

**[01:39:37.750] - Shirlene**

Well, that was my point when I had mentioned that when you get too deeply caught up in the emotional stuff around HIV and AIDS to let it out rather, than to hide it, don't bury these things inside you because

you don't never know how the other side is going to respond. Most of the time, I can say that I've heard people disclose 75% of the time, people embraced it. Instead of them getting the reaction that they assumed they was going to get, you just told your friend for the first time, "listen, friend, I got something I want to say. I was diagnosed with HIV." She just going to jump up out of her seat and run 100,000 blocks away from you. I don't want to be in your corner anymore. Or she's going to say, "oh, for real, girl, you should have told me." She embraced you, hugged you, and not in a pity way because she can see that you put together, right, that you got it. You're doing what you need to do for yourself as a person with AIDS. So they don't embrace it. People around me, a lot of most people embrace it because most people don't think I'm sick at all.

**[01:40:47.970] - Shirlene**

Like, you have no idea at all. But yeah, I'm sick. I am sick. I am ill. I've been sick and ill for a very long time. I've been battling these illnesses physically and mentally. I try to always be in charge of them and not let them be in charge of me. And I try to educate anybody else who needs that type of assistance because I know how hard it is to try to balance this. It's not an easy balance physically or mentally, because you walk down the street every day living with AIDS, not knowing who's going to reject you. Like you said, rejection is—me, I don't care about rejection. I ain't worried about you just going to have to reject me. But a lot of people are. A lot of people in spaces that they're so uncomfortable. I don't want to live the rest of that my life with AIDS uncomfortable, and I'm not going to live it uncomfortable. I'm not going to live uncomfortable.

**[01:41:41.990] - Lucas**

A lot of people are so alone because of that, because they're so afraid of that rejection, they just go into a clamp, into a shell. Like, and another great thing about the woman...

**[01:41:55.780] - Shirlene**

But that's a sign of depression and that's why we have the Woman Empowerment Group. You know, we're utilizing art as a tool for healing from mental health and depression. And if you can come to terms with who you are and what you have in this group, the healing begins, right? It has to begin somewhere. The healing has to start with you. But some people, I feel like they stigmatize themselves. Because you're thinking that you're a leper and that you're this sad person, this person that is not loved or won't be loved because they have—you're thinking that you didn't give the other party a chance to even have the opportunity to say what they feel because you won't disclose. Give the other party a chance. You'd be surprised what the answer you'll get. But if I'm looking into your eyes with fear, me and you were best friends for years, I'm like, I ain't going to tell them. I'm not going to tell them. I'm not going to tell them. I'm just not. I can't gain the confidence or the strength or the courage to tell the other party. Somebody that I known, say for years, we have such a strong bond that I can't just let this out.

**[01:43:08.030] - Shirlene**

You think that bond is just going to go away just like that? Just like that. Somebody that you know forever probably slept in the bed, played in the sandbox, went to the beaches together. You say you got AIDS and all that just ripped apart it just ends. It doesn't work like that. Give the other party a chance to embrace it with you. You're not giving them a chance. Don't stigmatize and hold yourself out. Give them a chance. They've known you for years. Even if it shocks them at first, they come around, right? They do come around.

**[01:43:43.640] - Lucas**

Not only they're shocked, but then they feel bad that they didn't know that they were not able to support you.

**[01:43:48.940] - Shirlene**

Exactly. Yeah. Why didn't you tell me? I will take you to your doctor's appointment. I'll help you with your medication, what you need? But if you're not giving them the opportunity, the stigma is going to sit, the depression going to sit, and you're facing you have to deal with it over and over and over again every day. So I prefer to let it out, and that's just my preference. A lot of other people's preference may be different.

**[01:44:15.830] - Lucas**

Then go. You let it out because by letting it out, you really ... it's like a butterfly effect.

**[01:44:22.410] - Shirlene**

Well, how I landed on the Daily News was Jennifer Flynn had told me to go meet with a reporter in Manhattan, and he wanted to talk about black women living with HIV and AIDS in New York City. So I said, all right, any assignment that was given to me, I would do. I went, met the guy, and I said, Hi, how are you? I'm Shirlene Cooper, African American with HIV and AIDS. I went home, went to sleep. That night, my phone started ringing, 05:00 in the morning. Everybody said, "Turn on the news." What do you mean, turn on the news? You know, I said in the papers, you're on the front page. And I didn't know he was going to do that.

**[01:45:04.620] - Lucas**

Wow.

**[01:45:05.210] - Shirlene**

I didn't know when POZ was putting me. I didn't know they were going to do it, but they did. I was okay with it, though. It didn't bother me, but my phone kept ringing. Not for sympathy, it was for strength. "Wow,

girl. Wow! We saw you in front page of the news. Hey, you're doing all good. Wow." So those was the kind of things that I received from people. That's what I received. And then I felt, you know, okay, so this is what I never thought that a person would turn me away. And I only had one person that did it was my nephew's girlfriend, and she was having a baby, and she invited me to the baby shower. And then somehow along the line, she got wind that I was HIV-positive. And when I got in the house, they told me, don't touch the food, don't sit in the chair, touch the plates, and stuff like that. So I figured it out that they knew. They just didn't tell me, and I left. Don't touch anything. And I left. Maybe three years later, it's Father's Day, of course, this is my nephew's children, and I'm having a Father's Day dinner.

**[01:46:13.460] - Shirlene**

And they come over to my house. I didn't treat them that way. I opened the door, I let them in, and they ate my food that I prepared. So all that was totally unnecessary, you know, but you can't tell how people how to respond and people how to act. I think now, in 2022, everybody should have some sense or some acknowledgment or some education on HIV and AIDS. So they know that you can't catch HIV / AIDS by just touching somebody, by sitting in the same chair, by drinking from a cup from somebody. That's not how you catch HIV and AIDS.

**[01:46:49.530] - Lucas**

Yeah, but you know...

**[01:46:50.790] - Shirlene**

So the ignorance is, like, the biggest challenge, which then comes the stigma, the hate, shame behind the ignorance.

**[01:46:58.990] - Lucas**

Well, so a lot of people use ignorance as a weapon, I think, to politicize people in ways that are beneficial to them by creating division as well.

**[01:47:10.500] - Shirlene**

Right. Divide and conquer.

**[01:47:17.230] - Lucas**

Yeah. But, we're united.



**[01:47:18.450] - Shirlene**

I think we do our best as people living, especially here in New York. New York is one very fierce city, and I think we've come a very long way from Pottersfield. When, you know, they were actually putting, just throwing the bodies in Pottersfield, now you're actually having funerals for people living with AIDS. People are living longer. So we've come a very long way. We do have a long way to go, generations to come. Going to look back and see how we handled, you know, living with HIV and AIDS. Like the black plague. We had to look back, what did they do? How did they survive, you know? Or they died out, right? Or all of them died out. What happens to us? What happens to the next plague that comes out? And what is going to do to humanity and stigma and housing and health care? How all these things going to be paid for? Who's going to be responsible? Where are our leaders when we need them?

**[01:48:17.830] - Lucas**

How are we going to deal with our Shirlene 100 years from now when the next crisis come over?

**[01:48:24.870] - Shirlene**

Yeah, exactly. Are we good now?

**[01:48:27.480] - Constantine**

I think so.

**[01:48:29.010] - Lucas**

All right.

**[01:48:30.410] - Constantine**

How do you feel?

**[01:48:31.550] - Lucas**

I feel good.

**[01:48:32.320] - Shirlene**

I feel good.

**[01:48:33.770] - Lucas**

Yeah.

**[01:48:34.110] - Shirlene**

We were just talking.