

**From the Media: Interview with Renata Simone
The Age of AIDS
May 30, 2006**

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JILL BRADEN BALDERAS: Thanks for tuning in to "From the Media." I'm Jill Braden Balderas with kaisernetwork.org. I'm joined in our studio today with Renata Simone with *Frontline*. She's the series producer and reporter for *The Age of AIDS*, which will air on PBS May 30th and 31st. It's a look back at 25 years of HIV/AIDS. Renata, thank you so much for joining us today.

RENATA SIMONE: Thank you.

JILL BRADEN BALDERAS: You've been covering HIV/AIDS for 20 years now. In putting this piece together, tell us one or two things that you learned that were new to you when you were doing your research.

RENATA SIMONE: All right. Well, it is an amazing story. And what we've tried to do is weave together the social, the political and the personal. And I think that we, in doing that braid and following the details, it wasn't until we looked at that whole 25-year spectrum that we saw some of the questions that are at the beginning are still at the end. So, the surprise was, "My gosh. We are still where we were 25 years ago." Denial and stigma are still rampant. Leadership is still maybe the most important ingredient and it's still true that the very basic kind of prevention - straightforward, targeted prevention - works. So, that was really the big surprise.

I think the other ones, maybe, are on the more personal level, where - I had been to, maybe, six or eight countries, until we

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started this project. In the course of making the films, though, we went to 19 countries total. And I was surprised at how, when you go from country to country, you meet the same people. There's the 12-year-old girl with three younger siblings, who has lost both of her parents to HIV and is carrying the whole household on her shoulders. You meet the young gay man who - you know, the emerging sexual man - and maybe he's 16, 17, and he thinks, "I'm impervious, and there's drug treatment, so I don't need to worry about it." And you just - that's surprising in a kind of negative way. Your heart breaks. But they're out there.

JILL BRADEN BALDERAS: Now, you mentioned how leadership is one of the key ingredients in the fight against HIV/AIDS and part of that leadership is political leadership. How did you all address the fact that AIDS and the politics of AIDS are so inextricably linked?

RENATA SIMONE: Well, we addressed it as best we could, head on. We looked at the early '80s and we saw the tremendous lack of leadership, lack of policy making, in the United States. Until, really, the mid- to late '80s, when you had the Americans With Disabilities Act and the Ryan White legislation, but by then, there were already 4 million HIV infections worldwide. So, that was not a very good policy period.

And then, after that, you had in '94 the big turning point of making AZT available for pregnant women, which was a very important political shift or policy decision in 1994, and the big global shift around the meeting in Durban, the U.N. Security Council

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meeting in 2000 and the formation of the Global Fund and PEPFAR, taking us right up to the present. So, there were these milestones of policymaking and they were attributable to specific leaders.

Because we're a documentary, and the nature of what we do is to follow people and their stories, we dug as hard and deep as we could about the Reagan story. What really happened? It's sort of common knowledge: "Well, Reagan didn't do anything." Well, we wanted to say, "Well, what did he do and why? What was the explanation?" So, we looked hard at that. We talked to the speech writer who wrote the speech he eventually made in 1987, his first speech on AIDS, and we talked to Margaret Heckler and her assistant secretary, to look hard at that.

We were tremendously thrilled to be able to cover the leadership in Thailand that was responsible for their 100-percent condom campaign that was so effective in reducing infection among sex workers. We looked into Uganda and we interviewed Museveni. We couldn't get access to Tabu Umbecki, unfortunately. But there are these tremendous examples of leadership that we cover in the piece.

JILL BRADEN BALDERAS: Now, some of those examples that you just spoke about showcase the differences and how leaders in different countries have tackled this issue of HIV/AIDS. What were some of the commonalities that you've found in the extensive interviews that you did?

RENATA SIMONE: That's a very good question. The commonalities, I think, run on both sides and, interestingly enough,

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it boils down to a very simple thing, which is that when leadership steps forward and says, "We have a problem; let's address it," and, in clear and frank ways, success follows and rates come down. When leaders are in denial or they allow policies that reinforce discrimination are left in place, the rates of infection go up. So, it does break down in very clear ways and leaders have a choice to either act or not act.

JILL BRADEN BALDERAS: The show runs four hours and I can only imagine that you did a lot of interviews that you wished that you could have included. Tell us some of the elements that you wish you could have included that ended up on the cutting room floor just because of time.

RENATA SIMONE: Right. I think one of the elements was some of the up-close stories. We covered the sweep. The series is intended for the widest possible audience and that includes my uncle, who still doesn't think AIDS is a problem and various other people, but we just wanted to be able to get as many people as possible into the tent. So, everything below that first level of what happened, what's the big sweep, we weren't able to go in deep. What we hope is that, through our web site, people will say, "Well, that was interesting. That story on Brazil where one woman sued the government and there were some policy people who agreed with her and things really changed."

But they can go to the web site and go deeper. So, in each place, I think of them as the scenes in the film as almost holograms,

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that they are the essence of what we shot. But there's a lot more. There are interviews on the web site and, of course, tremendous resources on the web, including on the KFF Source web site, and our web site links people to those things. So, it's like singling out a favorite child. There are a lot of things we do wish we could have put in. But, we've got them on the web site and on the web in other places.

JILL BRADEN BALDERAS: Now, *Frontline* hopes to use this history after the broadcast as an educational tool. How do you see that taking shape and how will you work the different organizations to make that happen?

RENATA SIMONE: It's a two-way partnership, no doubt about it. There are people out there who do what they do better than we could ever imagine, in terms of reaching different populations that can help, either, as I say, from that policy level, or right on the ground, you know, teaching high school, teaching middle school, and what we hope - people think AIDS is over. The media spotlight, in general, sort of hits AIDS sometimes in a confusing way. You know, "What was that about?" And then it's gone. And, so, what we hope is to give the documentary a longer life than just that four hours on the satellite and we will take segments, case studies from the films, we'll use some of those elements that I mentioned a minute ago that didn't make it in, but that we shot, and make case studies that will be available to graduate schools and healthcare professions and journalism, college-level classrooms.

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Particular outreach we're doing is to Title I schools and we're looking at doing some things on the Hill with the staffers because, yesterday, Anthony Fauci mentioned to me, "You know, there's a whole new generation of staffers in Congress. They weren't there. They don't know the history of the epidemic. They don't know how the wheel was invented. They don't know the mistakes of the past and the solutions that were created in the past." So, we're hoping to outreach to that whole range of people and really give this document a long life. We don't think it's a definitive history, but we think it's sort of a definitive outline of history.

JILL BRADEN BALDERAS: Now, this documentary is a look at the past 25 years. Where do you see us being in the next 25 years in the fight against HIV/AIDS?

RENATA SIMONE: I'm not clairvoyant. What I know about today in some ways is encouraging and in some ways is discouraging. I think in 25 years we may see an extension of where we are today. The increasing bifurcation between the people who have access to treatment and people who don't have access, the continuing disparity in the responsive leaders that some continue to step up and some continue to deny they have a problem in their countries. And I think what worries me most is something we've talked about - complacency. I think that's a very dangerous problem.

And one of the take-home messages of the series is really the realities of treatment. That it's not insulin, it's not a

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standard product with which you can go and live the rest of your life, it's something that your body is constantly in chemical negotiations with the drugs and your virus is trying to outsmart it all the time. So, treatment is not a final answer and, as Richard Holbrook says at the very end of the program, "We have the tortoise and the hare. The tortoise is its own race to get treatment to as many people as possible, but the hare, who will win the race, is transmission. It will always outpace our ability to keep up with treatment." And I'm afraid he's right. So, I think the main challenge for the future is prevention. And the good news of that is it works.

JILL BRADEN BALDERAS: Last question. What do you hope your viewers will take home from the show? How do you hope that they will be inspired by watching it?

RENATA SIMONE: Well, maybe it's just where we left off. I think the fact that prevention works is tremendous. You know, I stayed reporting on AIDS partly because there is so much suffering in the world that the opportunity to do something about preventable suffering is a tremendous opportunity, and AIDS is such a broad-spectrum problem. It covers every discipline, so no matter who you are, no matter what your field of work is or what your family situation or friends, there's no one who can't do something about AIDS, who can't get involved and help do that, alleviate or address preventable suffering.

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You know, Zacki Achmat, at the very back, another end quote for this series -

JILL BRADEN BALDERAS: For our viewers, who is Zacki Achmat?

RENATA SIMONE: Zacki is the head of the Treatment Action Group in South Africa, a very HIV-positive man who took an absolute, personal stand about a global issue and said, "I will not take treatment until it is available to all my fellow South Africans at a reasonable price and access supported by the government policies." And we go into the Umbecki story extensively on the second night. But Zacki says, "We cannot win against HIV. It's already too far gone. There are too many people suffering already. But we can mitigate the disaster and, in so doing, we can show our humanity." And I think that's a tremendous opportunity for all of us, so I do hope that our viewers see that opportunity at the back end and join it.

JILL BRADEN BALDERAS: Renata Simone, with *Frontline*. Thank you so much for joining us.

RENATA SIMONE: No, Jill, thank you.

JILL BRADEN BALDERAS: The series, "The Age of AIDS," is scheduled to air on PBS May 30th and 31st. I'm Jill Braden Balderas with kaisernetwork.org. Thanks.

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