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SARAH SCHULMAN: Where we’re going to start is if you could tell us your name, how old you are, today’s date and the address of where we are?

ANNE-CHRISTINE D’ADESKY: Okay. Anne-christine D’Adesky. Forty-five and thriving. The address?

SS: Uh huh.

AD: 33-45 22nd Street, San Francisco, California, 94110.

SS: And today’s date?

AD: Today is the 15th of April – tax day, I believe.

SS: Where were you born, Anne?

AD: I was born in Marquette, Michigan.

SS: I never knew that about you. And where did you grow up?

AD: I grew up mostly in central Florida – East Coast beach towns, but I spent a lot of my time – summers and vacations – major vacations – in Haiti.

SS: Why was that?

AD: My father was born in Haiti and my grandparents lived there, and it was a cheap vacation for us to go.

SS: So, did you grow up bi-lingually?

AD: I grew up in a primarily French-speaking household, and English was the second language for my parents.

SS: So, how did you leave Florida?

AD: I left Florida when I was 18 or 19. I had started having my first lesbian relationship, and I was feeling intellectually very bored in Florida. And, I’d been a tennis
player, and I was going to be a professional tennis player and decided that I would not do that, and instead I went north and I went to Barnard and got involved in the lesbian lifestyle of New York City.

SS: So, were you out to your family before you went to college, or before you went to Barnard?

AD: No, I wasn’t out to my family. I wasn’t out to myself. I didn’t identify as a lesbian, particularly – even, for quite a while, the period I was involved with women. My family thought that I was sexually ambiguous, when I was extremely young.

SS: And, how did that make them treat you?

AD: Well they had a lot of homophobia in my family. When I did come out, I was written out of the family will for a year. I didn’t know we had a family will, so it wasn’t a great loss. But, it was very difficult for my father, in particular. My mother had already passed away. But, my family had a lot of homophobia, and I had a lot of internalized homophobia. So, I think that that contributed to my slow coming out. But, it was also, just in terms of how I identified internally. I hadn’t felt any particular stirrings or longings of same sex attraction, prior to getting involved with someone.

SS: So, when you got to Barnard, and you said you got involved in the lesbian world – did you become politically active?

AD: I became politically active – not on gay and lesbian issues. Basically, I started – at that time, it was the early ‘80s, and the big issue was, really, the Peace Movement, and the deployment of Pershing cruise missiles in England. And so, I started – my first political action, I remember, was the Women’s Pentagon Action. And, I met people who just impressed me as activists. Aside from the sort of younger women, there
were some really seasoned activists like Grace Paley. And, I really felt a lot of interest in spending time with that community. So, I helped to organize, or be involved in that action and I think, from that, I started to feel more of a political lesbian identity. Before then, I think, I had just been involved with women and, sort of on a personal level, had been working out things. But, I hadn’t really thought about it, in terms of any kind of real organizing or any sense of – I guess – focus for my own work. So, from there, I spent a memorable summer at the Women’s Peace Camp, in upstate New York.

**SS:** Seneca Falls.

**AD:** I was then maybe on to my second girlfriend or third girlfriend. But, I think, at that point, I was really making a shift from sort of an observer to a participant, more internally. Because I was becoming a writer and a journalist, I’ve always had a slightly divided identity, where I feel like I’m torn between observing events and recording them and participating in them, particularly in those early days. I struggled with – should I document this? Or should I get arrested? And that has always been a tension in my activism. But there, I definitely went to the side of just being really fully participatory and I think that’s when the activism really kind of came together for me.

**SS:** What were some of the strategies that you participated in at Seneca?

**AD:** I think it was a combination of a lot of discussion – which I think women are famous for and lesbians are especially famous for. But, I think also, thinking through what I felt was a strategy that then later became part of the AIDS work, as well, is, rather than talking about what it is that you want to do without a sense of a goal, it’s to really think about the object of your activism and then use that as the framework of your
discussion and the framework for thinking through the types of actions that could be useful to get you to that goal.

So, it wasn’t just processing for the sake of processing. And I feel like, that was the first, sort of, direct action experience that I had had. And there were so many different perspectives and so many different women. And again, I think I was impressed by the women who had been involved in early reproductive rights work. I had done a little bit of that in New York around groups like CARASA and, at that time, the abortion fight had been something that was really, really strong. And, I think I wasn’t as involved in the reproductive rights, because it was just my first foray and then, at the Women’s Pentagon Action, I began to really see the connections between the policy issues and civil rights in a very direct way and then, to sort of take the next step and decide, okay, I’m going to actually invade this army base and get arrested – for me, was a step.

It wasn’t something that I particularly looked forward to. I’ve never, ever enjoyed getting arrested or going to jail. It’s not been one of my favorite things to do. I’ve done it repeatedly, but it’s never been something that I’ve enjoyed – the way some people really enjoy it. It’s not my lifestyle, but I always felt that it was something that – I took it on with a lot of seriousness.

SS: So, after that, what were some of the other movements that you were involved in, before ACT UP?

AD: The peace movement, reproductive rights. In 1982, was when I first began to do my AIDS work, and –

SS: Let’s wait. Hold that for a minute.
AD: Yeah, just as a journalist, I began to do that work. But, the real issue that was most important for me in those early years was human rights work that I was doing in Haiti. Because my family background is Haitian – my family is a very wealthy family from Haiti, and there was a dictatorship at the time, and I felt that I was in a position to really document something from an insider perspective and, also, speak out. So, I got involved in human rights reporting, and would go to Haiti and come back.

SS: Who were you working for?

AD: I was working for a lot of different places. I first started doing work for progressive newspapers and magazines, like In These Times – eventually, places like the Village Voice or The Nation. But, initially, it was really smaller news agencies and things that were definitely identified as progressive. And then, eventually, I became a stringer for the San Francisco Examiner, of all places – for a period that was already now in the mid-‘80s.

SS: You were going back and forth to Haiti?

AD: Yeah, going back and forth to Haiti. I had also gotten involved, after I had gone to Columbia to go and get a journalism graduate degree – and one of my first jobs, after that was working with Robin Morgan, who was, I think, still at Ms., or an Editor-at-Large at Ms., and she was doing an anthology on the global status of women. So, I worked on that project for two years. And, I think that that’s where I started to really focus on global work, and met very interesting people through that project. But, the human rights piece of it emerged then. I wrote my first essay on Haiti – sort of under a pseudonym and sort of took a deeper step, in terms of real human rights work.

SS: Now, were you out as a lesbian in your human rights work?
AD: It depended on the circumstance. I don’t think I ever hid my life, but I don’t think it was something that was overt, particularly. I often traveled with a girlfriend or things like that, so, certainly people knew. I don’t think that people have ever had an illusion that I wasn’t, but I think that’s really different from sort of presenting yourself as a lesbian and organizing as a lesbian. So, I wasn’t doing that, particularly, in Haiti, and I also still felt, even – and always has been a kind of tension in my personal life – which is that I feel like I politically identify as a lesbian, and I’ve lived my life with women, but I’ve always had a broader, internal sense of my sexuality. And so, I’ve always had that bit of struggle around feeling a little too hemmed in.

And, initially, I judged that as, like, oh, this is just internalized homophobia, and so, I really was overt in my lesbian identity. But, now that I’m 45, I feel like I can kind of settle into that place that I’ve always inhabited, which is just a broader sexuality – even though I’ve politically and culturally and socially identified as, you know, a lesbian and part of the gay and lesbian movement.

SS: Did you feel that the other human rights people that you were involved with politically would have responded differently to you, at the time, if you had been completely out?

AD: I don’t know. In Haiti, I think one of the things that I was always very aware of was that I was white and I was working in a predominantly black Haitian movement. And, what impressed me was getting solidarity, feeling supported, in fact, by a community that I think, when I was in Haiti, I was treated as a race traitor, always, by the elite and the middle class of people who thought I should have solidarity with them. And, politically, I was very openly speaking out against them. And so, I think that if
anything, I was conscious of feeling embraced and was probably – there were probably times when I felt a desire to be able have more contact with lesbians and gays in Haiti. I tried, but people were not that visible at that time. I did meet some of the people who later became AIDS activists in Haiti, at that time. But they found me, I didn’t find them. So, it wasn’t an easy place to be an open lesbian or gay man in the early ‘80s – at least, I didn’t find it so.

SS: And how did your family respond to the fact that you were taking the – waving the flag of the other side, sort of speak, in Haiti?

AD: Well, my mother had passed away. My father was frightened for me. He was afraid I’d get killed. My extended family was very upset. They regarded me as a direct threat to their status and their safety. We had some encounters. But, I think that at the same time – it’s very typical of families, where you have this division. A lot of families that I’ve known have been Latin American, South American. We have one side of the family is politically taking one side and the other. I think they also felt respect, and I think that they sometimes felt that it’s because I could escape to the United States that I had taken the positions that I had. That, if I lived in Haiti all the time, I actually wouldn’t feel the same level of, I guess, solidarity with the sort of struggle of everyday Haitians, and I wouldn’t be as critical of them for their privilege and how they used their privilege.

SS: So, when the dictatorship fell, how did that affect your status?

AD: I think I felt a little more comfortable – that I wouldn’t be as physically threatened, working as a journalist. I felt really happy.

SS: I mean, regarding your family.
AD: Regarding my family? Well, things didn’t change overnight. The dictatorship, as I see it, didn’t really end for quite a long time. So, that struggle continued only until, maybe about three or four years ago. And now that things have changed so much, I think that they – there’s sort of a sense of – well, we’re family, so we may as well just make peace with each other, and we just totally disagree.

But things were difficult. They were very difficult for awhile. I think it’s strange to be working in a country and to feel like you’re regarded as the enemy of your own family, but that’s a position that you take. I feel that a lot of people took it.

SS: So, when did you first hear the word AIDS?

AD: I think my first was probably 1981, 1982. I was in Haiti, and there was an epidemic going on, and I knew some physicians and that’s my own awareness. Some of the first reporting that I did was for the New York Native, and it was on Haitian Americans in New York, where Haitian Americans were also being really stigmatized, and that’s kind of how I got into the AIDS work and into the meshing of the gay –

SS: What was the chronology in terms of American AIDS? Were Haitians identified first, or gay men?

AD: I think the gay men were identified in the media first. I think that in Haiti, when Haitians were identified, they were assumed to be gay, because of what was going on. They were almost immediately, sort of officially branded that way. Their policies, in terms of immigration, were sort of set up so that right away Haitian Americans were – they weren’t able to give blood. It was sort of: hemophiliacs, heroin users – the four H’s – and homosexuals and Haitian Americans. So, I think that that made the whole discussion of AIDS in Haiti a very, very different thing.
But, I came into it, I think, again, through an issue of human rights, through the issues of immigration, through the issues of policy and justice – not so much that I was knowing friends who were Haitians who were sick or dying of AIDS. I came to know quite a lot of people. But, for many years in Haiti, it wasn’t something that was – I don’t think there was a death certificate that was signed that said it was HIV, until maybe a few years ago. Even now, people die of tuberculosis; they don’t die of AIDS in Haiti. But, so many people were dying that, after awhile, it became a really obvious thing.

SS: So, you were writing about Haitian AIDS for a gay newspaper, the *New York Native*.

AD: Yes.

SS: Was the mainstream press covering Haitian AIDS at that point?

AD: I think that there were some coverage here and there – people who were involved in Haiti, who might write an article here or there. There was some writing in the medical journals. Some of the Haitian doctors in New York were trying to get the attention. But, I think a lot of the focus was really on the safety of the blood supply. It had a huge impact on people being able to get refugee status here. And, there was still the post – in this whole period of dictatorship – so, people were fleeing Haiti, trying to get status here, and being rejected, because of HIV or concerns around communicable diseases. So, so much of the organizing here was really only around that. It wasn’t really on the issue of the rights of PWAs or anything like that. It was just very specifically, we’re not gay, we’re Haitians. We’re being discriminated against, simply because we’re blacks. So, there was a racial discourse that was really – the undertone of the official policy was racism. And, within Haiti, there was a real backlash. People were terrified to
come out in any way, or be seen as gay. So, in retrospect, if I had been living all the time in Haiti, there would have been a huge amount of work to do that I didn’t get to do, because I was more in New York, and was never done. Like, the Haitian AIDS epidemic hasn’t been documented in that way – what people suffered. But, I would kind of dip into it when I was there.

**SS:** So, in terms of epidemiology – now, with all the knowledge that you now have, were these two different phenomena? The AIDS that we saw in the U.S. with gay men, and AIDS that we saw in Haiti at the same time?

**AD:** In terms of disease? No, I think that the disease developed around the same time, but I think the sources were different. I think that there were – it’s really difficult to know what the sources are for Haiti or for the Caribbean, but quite a number of Haitians were professionals who were posted to places in Africa, where there were epidemics developing at the time – like Kinshasa, Zaire, and some of those early cases were known to have been people who were in Africa, so heterosexual – again, when your sexuality is so stigmatized, how can you possibly be really able to document whether someone was exposed through gay sex or through straight sex. And, at the same time, the blood supply in Haiti was not very clean. Haiti is the poorest country in the western hemisphere. There has always been sales of commercial blood. There were, for a period of time. So, that’s another source of unclean blood.

There was, and always will be a lot of sex work in Haiti because of survival sex, people are so poor. And, for a long time, gay men and bisexual men would see Haiti as a place to have cheap and easy sex. I mean, there’s a lot of prostitution that takes place. So, again, I know gay men, including some that I met through ACT UP, who would go to
Haiti and it would be a place where they would have a great time, sexually, and that wasn’t always sex work – that would have been sex with gay men who were meeting other gay men. But, I think there’s a lot of different sources for it. So, I can’t really say, and I don’t think it’s really been well documented, but ultimately, I know that in Haiti, the discourse is that, you know, it’s a heterosexual disease. I’ve always thought that it was a disease in which there’s a lot of gay and bisexual men who are also men who have been married because of the culture. And I think that’s true in Africa, too. I think that there’s a really big, hidden gay and bisexual HIV epidemic – it’s just that with culture, we can’t really nail it down.

SS: Okay. So, when did you start to become active around AIDS, in addition to being a journalist?

AD: Well, I think that my activities began in the form of things like calling meetings of people or doing petitions – those kinds of things, initially.

SS: Around what issues?

AD: Around AIDS issues.

SS: In Haiti.

AD: In Haiti, for example. And then, I think, here, very early on – I think, certainly, you know, with – I don’t know the timing, even, when the first ACT UP demo was, but whenever that was – that was the first ACT UP demo that I went to. I think before that, I had just been kind of meeting through people through journalism. I ended up at the New York Native because it was a place that was clearly trying to figure out what was going on, and was one of the only places to write about that, at the time.

SS: So, how did you get to ACT UP, do you remember?
AD: No, I don’t really remember. I think it was probably just one of the activities that was going on, in terms of AIDS work. And, I was either covering it, or going there because I wanted to get involved in it. I don’t really remember. I just remember that it was – I remember hearing that it was going to be – I was going to meetings and at some point, there was going to be a big action. So, I don’t know who or from where, but it was through the gay men that I was working with at the Native, and around that circle that I knew people who were organizing ACT UP –

SS: Like who?

AD: Oh, Darrell Yates Rist.

SS: “Darrel Limp Wrist” was his nickname. Ann Fettner.

AD: Patrick Merla. Some of the people who were – a number of people have died who were with the New York Native, but that would have been the sort of core people who were gay journalists covering gay issues in the community.

SS: So, when you came to ACT UP – you had been in all these different kinds of movements before – where did it fit in, in terms of your previous political experience?

AD: I actually think it was the closest to the reproductive rights work, because it was the angriest. People in reproductive rights were really angry. I didn’t think the people in the peace movement were as angry at all. I thought that they were sort of morally high ground in the peace movement, but I don’t feel like there was the same direct stake. And, I think with AIDS, is was such a direct thing, because people were terrified. So, I related to that movement, because I was coming out of Haiti, where a lot
of people had died and were dying, and it felt much more urgent to me. And so, it was compelling in that way.

SS: So, how did you first plug into the organization?

AD: I think I just went to meetings. I probably wrote about, I don’t know. I have to go back and see if I wrote about it.

SS: Did you join any committees?

AD: I did actions. I helped out on actions. I was always kind of struggling, I think, after awhile between writing – because I was writing about it. Again, I’m not sure for who. Maybe *The Nation*. I don’t remember, I’d have to go back.

But, somewhere in there, I just remember working on specific issues. Often, I did research or thought about the action – planning for an action. You know, working in affinity groups. I think for me, it was a level of combining my then developing interest in what I could find out about HIV. I think the reason I started writing and getting really involved, and this has become my career, is because I felt that there was a real lack of knowledge about what was this virus? And, how was it killing people? And, I felt intellectually that that was compelling. I felt that it was not something that a lot of people were writing about for the community. And so, I felt right away that there was this niche and I personally felt like it was what I could do.

SS: So, you had no science background?

AD: But I had studied biology a little bit in college. I didn’t have a background, but it was something that I felt very at home with.

SS: Now, wasn’t there a culture in ACT UP of non-science people, developing expertise in scientific areas?
SS: What do you think enabled people to take that step?

AD: Well, I think that – the biggest thing for me is just the motivation you have when you think you’re dying – is that you try to find out. And, if no one has the answer, you still have to go out and get it. So, since there weren’t answers – this wasn’t like cancer, like a 20 or 30 or 40 year kind of illness that people had already decided what the strategy was for dealing with it. And, I think that that’s – in the same way that people felt empowered to take on institutions, they felt empowered to take on the science, because it was totally new science. So, it allowed them to have that kind of role. It allowed them to say to scientists, we need you to study this, and then, to see that they could learn it along with the scientists. And, I felt, for myself that, very quickly, it became obvious to me how much could be done, by anyone who just had an interest in getting involved.

SS: Okay, so give me some specifics? Tell me a scientific question that you had, and how you proceeded in investigating it.

AD: Well, I’ll give you an example. I remember, one of the early experiences I had in Haiti was – I was invited to an exorcism of a man who was dying of AIDS. And, what I discovered was that he had dementia, and he was being prayed for and this was the kind of care that was available – palliative care. People were just trying to sort of usher this person from one realm into another. And, it was very moving to me. And, it was also frustrating to realize that he had a serious disease that was affecting his behavior and his brain. And, I took that experience and went back to the states and tried to find out about HIV in the brain, and then shared what I knew with physicians in Haiti.

SS: So, when you say, tried to find out – what did you do to find out?
AD: I went to talk to people who were experts on the brain.

SS: Like who?

AD: Oh, at the time – let’s see, who became people that were – like Justin McArthur at Johns Hopkins has become very well known for HIV –

SS: So, you just called him up and said, “Hi, I’m a journalist.” And, he was willing to talk to you?

AD: Yeah, yeah.

SS: So, what was – at that moment, what was the understanding here about dementia and how it functions?

AD: Well, I think people had a belief that these were simply opportunistic infections that were manifesting as an aspect of late-stage AIDS. And, I don’t think that they really sussed out what’s HIV, what’s not. They still haven’t done that, to some extent.

But, I wanted to know, what could I do to help people who were developing this. And, I remember, one of the things we ended up doing in that Haiti trip – or, one of the later Haiti trips – a similar situation was going down with injections of B-12, because we thought, at the time, that B-12 could somehow help people who were having that kind of dementia. People like Jon – what’s his name? – Greenberg, who was very involved in complementary care. We would talk for hours about the brain, and try to think about all the things that you could do to help someone. So, I felt like, it was thinking about things that were happening here, but also, how they could be applied in a context where you didn’t have access to all this kind of stuff. So, I was always sort of aware of the discussions taking place in ACT UP were on one level, and then, the reality in Haiti was
at a totally other level. And so, I think, for me, it was straddling those things. If anything with ACT UP, I felt like I was taking information that was being developed in a context of ultimately still remarkable access, and then trying to see what was useful to a place that didn’t have any.

**SS:** What was the trajectory of treatment for dementia?

**AD:** Pain.

**SS:** I mean, what kind of treatments –

**AD:** Well, depending on whether it was cryptococcal meningitis or things – people eventually developed those kinds of – various kinds of medicines. But, I think, in the beginning, it was, even trying to identify the illness was trying to diagnose it.

**SS:** And what is your understanding now, of the relationship between HIV and dementia?

**AD:** Well, I see dementia as being caused by any number of infections that really can become, sort of a manifestation of full-blown AIDS. But, I also feel that it’s still unclear the extent to which HIV infection itself affects the brain. And, it’s always something I kept my eye on because it’s a reservoir, and I think that it’s still one of the reservoirs for the virus, in people who are treated. So, I’ve always kept my eye on it, in that way, and researched it.

**SS:** Have your feelings changed over the years about the relationship between HIV and AIDS?

**AD:** Well, I’m certain that they have, but that’s too general a question, you have to ask me – what do you mean?
SS: Well, early on – okay, when HIV was first identified, there was enormous controversy in the gay community about whether or not HIV was “the cause of AIDS.” And, eventually, a general agreement was formed that, in fact, it is – even though there’s always been a dissenting voice. Do you remember participating in those debates?

AD: Yeah, I felt very open. I’ve always felt that new viruses are discovered all the time, and that there’s a lot of them we don’t know about – SARS is a case in point. I remember, at the time, way back, at the New York Native, writing an article about African Swine Fever – not because I was really thinking that it was African Swine Fever or HIV, but because there had been an epidemic of a certain kind of disease in pigs and in areas where HIV had been very prevalent – or AIDS had been very prevalent in Haiti and the editor at the time really wanted me to look into this. And I thought, sure, I’ll look into this. I’ve always believed that there are co-factors that will make a disease more prevalent or can impact on it. I mean, TB, Malaria – these are the kinds of diseases that are being looked at in other parts of the world that are sort of endemic. I’ve always been open to investigation. I’ve never doubted that HIV was involved in AIDS, though. Never.

SS: Do you believe that there are co-factors that have to be present with HIV, for AIDS to develop?

AD: Not necessarily, no. But, I think, that it’s like any disease, it’s complex, and people have individual histories and that there are environmental factors that are really, really significant, in terms of how that disease will develop.

SS: Like what?
AD: Well, Malaria is a good example, or TB. These are illnesses in which people’s immune systems are really compromised. So, when a virus like HIV comes along and has that much more opportunity to develop really quickly, have a certain kind of course of disease that it may cause. People can develop recurring hepatitis, who may not, otherwise have had an active case of hepatitis – things that are part of a general environment of illness.

SS: Okay. So, when you were in ACT UP, would you say that your major activities were related to research and science?

AD: No, I think that my major activities were participating in an overall discussion about many things. I think that I was actively involved in the weekly and overall policy discussions around specific actions, specific targets. I didn’t choose to actively get involved in any particular committees, except selectively and at different moments. There were times that I would work on a media committee, or I got involved with treatment for awhile, or I would drop in on the immigration one or I would get involved in women’s issues. But, usually, it was specific to an action, because I was interested in a lot of it.

SS: Let’s talk about some of the things you just mentioned. What activity was going on around immigration?

AD: Well, the issue that still is just as scandalous, which is that the United States forbids people who have HIV to come into this country.

SS: And was there an immigration committee in ACT UP?

AD: There was an immigration committee. There were actions.

SS: Who was on it?
AD:  Oh God. I remember the people being involved on it were the people who were sort of doing city actions. So, I think it was a crossover of the city actions group. But, when I think – so many people come into my head right way – so many – James Learned. I think more about actions than I do about –

SS:  What were some of the immigration related actions?

AD:  Well, let’s see, immigration – protests. INS protests.

SS:  At the INS?

AD:  At the INS. Rallies. I know for myself that I spent time going into the Haitian community, talking to them about what was happening, making flyers, translating flyers into Kreyol.

SS:  Were there any conscious coalitions between ACT UP and Haitian groups working together on actions or projects?

AD:  Very, very little. I felt that it was always – that I was a liaison from an outside group that was coming to the Haitian community. I think that ACT UP was really perceived largely as a gay group by the Haitian community for a long time, and I don’t think that people really felt that it was the place that they would go to do organizing.

SS:  Did they not want to be associated with gay people, because of the stigma?

AD:  No, I just don’t think that there were – there weren’t natural links being created. ACT UP wasn’t reaching out to the Haitian community. That happened very late in ACT UP’s development – that it thought about communities, really outside of the
umbrella of, I think, the core gay and lesbian and maybe, sort of general civil social justice networks that were really Manhattan based.

**SS:** So, if ACT UP had a demonstration around immigration, would it just be an ACT UP event? Or, would it be in coalition with other groups?

**AD:** I think that it would sometimes be in coalition with other groups, but I thought that it was often in name only. I feel like people would individually go out and drag people in from other groups. But, it wasn’t that those groups were being asked to define the issue, speak for the issue in a way that was really meaningful for their community. It was usually, let’s have this action and who should speak. And, that really was the way that ACT UP did its thing for a long time. It was one of the criticisms that people had of ACT UP – was the fact that it acted and then thought. And, I think that that was its strength and its weakness, in terms of coalition work.

**SS:** I just want to ask more about the INS thing. Do you know – did ACT UP ever had meetings with the INS?

**AD:** I think that, really, they were protests. I think that the message was delivered to the INS or to people involved in working on New York City immigration issues – the office of whatever it would be. You know, whatever mayor. I remember Koch was a direct target for ACT UP, for good reason. Immigration, I think would have been one of the issues that he was being sort of targeted around and about.

**SS:** What was Koch’s role in AIDS?

**AD:** Well, I think that – I personally remember the amount of anger that I felt at Koch. I felt that it was essentially a lip service paid to a government response to the epidemic, in a city that was being devastated by AIDS. I think that the Koch
administration did respond nominally, and it didn’t respond with any sense of urgency or with the funding that really would have allowed them to both identify who was at risk; put in place appropriate targeted prevention services. And, I think that to this day, I ask myself, how much of that had to do with the gay men who were actively responsible for the Health Department policies in the City Department of Health, at the time.

SS: Like who?

AD: Well, I remember – I don’t even know if the dates would be right. But, I remember people like Marvin Bogner and things like that were gay men. I don’t know if they were open in their gay life. But, I think Ed Koch – I’ve always regarded Ed Koch as a gay man, who wasn’t officially out on the job. And I wonder to what extent their concern about being – about homophobia sort of prevented them from having a more appropriate response to a public health epidemic of a communicable disease that was sexually transmitted.

SS: Okay. Let’s talk about some of your friends in ACT UP who died of AIDS. Who were some of the people that you were close to?

AD: Aldyn McKean.

SS: Tell me a little about Aldyn, and your experiences with him in ACT UP?

AD: I got to know Aldyn through ACT UP, and we saw each other, sometimes, outside of ACT UP. So, it wasn’t just a friend at ACT UP. I always liked him, because I felt that he was someone who one, retained a sense of urgency and seriousness about his work as an activist, but also really knew how to play. And, while he was very righteous in his politics, he was humble and understood that he didn’t always know everything, and
he was, I felt, a very good listener. And, so, I appreciated how he was an activist. It was one of the things that drew me to him.

SS: Did you work on any projects with him?

AD: Yeah. I don’t think he was ever in an affinity – maybe once he was in an affinity group with me.

SS: What affinity group were you in, do you remember?

AD: Oh, it depends on what – I don’t know the names of our affinity groups. I have a bad memory.

SS: Who were some of the people you were with?

AD: Let’s think – the big one that shut Grand Central. That was a big action.

SS: Day of Desperation.

AD: Day of Desperation. That was one in which Alden and I hung out a lot.

SS: What was that about?

AD: Day of Desperation? It was a day of desperation. I believe World AIDS Day was the occasion, and it was a multi-pronged attack on the city to just kind of raise people’s awareness that the day itself was desperate, that the situation was so urgent. And, one way to do it was to cause commuter traffic to slow down, or to try and close the city down. So, it was really effective, because there’s nothing that pisses New Yorkers off, beyond – I mean, I think traffic is the number one issue that unites and divides New Yorkers. So, it was really effective.

SS: What did you do that day?

AD: That day, let’s see, I think I remember getting up really early – or, maybe the night before, the week before, I was doing a lot of location scouting, trying to see
what places were appropriate for hanging a banner. I think we hung one off the Brooklyn Bridge. We hung one off of the overpass to the East River Drive. I was with a group of girls.

SS: Who was there?

AD: I don’t know. I mean, I think my girlfriend, at the time, might have been one of them.

SS: Was that Garance [Franke-Ruta]?

AD: No.

SS: Allison [Frohling]?

AD: I don’t know, I don’t know.

SS: Oh boy.

AD: But, I know that we were doing a lot of location scouting, which is always fun. There were real social aspects to activism. And then, really seriously thinking about how to – what we were going to do; what site we were going to choose. I did some media work – which is just really being available to speak to the media, communicate the message.

SS: Who was the director of media at that time?

AD: I want to say – God, this is going to be really embarrassing. I can’t say this on tape. Why am I spacing out on this? She was working a lot with city AIDS issues. She was facilitator –

SS: Ann Northrop?

AD: No, she’s kind of pale, short hair, she teaches school. No – it was a woman. Ann Northrop was always involved in media stuff, but – I remember that Day of
Desperation was – a lot of it was really thinking about where you could be the most useful and the most strategic. So, helping out with graphics – I always did a lot of wheat pasting with ACT UP for whatever reason. That was always something that I felt comfortable doing. I remember wheat pasting for that action and getting arrested.

**SS:** In Grand Central or outside?

**AD:** Outside of Grand Central. I remember getting arrested – let’s see, that could, yet, be another action, up near the Triboro Bridge. That could have been another action, it was the same day.

**SS:** Let me ask you –

**AD:** They all blend together to me.

**SS:** Okay, well, you were involved in a lot of treatment questions, and your friend John – what was his last name?

**AD:** Greenberg?

**SS:** No.

**AD:** John Cook.

**SS:** John Cook. Was there ever a time where your research interests corresponded with his medical needs or the medical needs of any of your friends?

**AD:** Oh yeah.

**SS:** Could you give some specific examples?

**AD:** Well, I remember starting with Haiti – that fungal infections or something, I was – I wanted to know, I wanted to know about parasites, because Haiti has a lot of parasites. So, finding out about what kinds of drugs worked was something that I wanted to know about. And sulfonamide drugs, and antibiotics. Those would be the things that I would
ask people about and doctors about. I remember, I got involved in T&D – Treatment and Digest [Data], which is one of the committees of ACT UP that later became TAG. And, there was a project that they were working on called Countdown 18 months. It was a project in which – trying to figure out what compounds might be useful against HIV, but also for opportunistic infections. And I was always kind of involved and interested in, again, what worked for some of the infections that people were getting in Haiti.

**SS:** What did work? Do you remember?

**AD:** Well, I think that one of the things that worked in Haiti that was never really done here, but was so significant was really active TB prophylaxis and a strategy of controlling HIV, which was around treating STDs and TB. That, really, was what they did and it really worked.

**SS:** How did they treat it?

**AD:** Well, they aggressively treated TB.

**SS:** With what?

**AD:** With any number. I mean, there’s a bunch of different medicines you can use to treat TB, but I think that TB was the killer of people with HIV. They were dying of TB more than they were dying of HIV, in other words. And so, it was a way of, I think, also de-stigmatizing HIV. So, I felt that here we didn’t really focus on TB until very late in the epidemic, whereas in Haiti, it was, like, let’s find out who’s got active TB or recurring TB, they probably have HIV. So, it was a way of screening for TB – I mean, for HIV – and a strategy that was working – literally, on the kind of protocols you used for TB, but also the infrastructure for TB management – things they had and – I think
that’s only something that we’re now seeing in other countries because it was just more active there than here.

**SS:** So, what was John’s treatment?

**AD:** Well, as I say, with John, there were some things that we had to do that were very intensive. He developed KS and so did another friend of mine, Kiki.

**SS:** Kiki Mason?

**AD:** Kiki Mason. With John, it was – there were things that were available. They were initially trying things like Bleomycin and Vincristine. These were drugs that were used – chemotherapy drugs. Not always successful, but at that time, there were efforts to identify compounds that now have become the compounds that are used, like – I think, Daunorubicin and Doxol. And, at the time, those compounds were in the pipeline, and the drug companies weren’t willing to make them available for compassionate use. So – just on a personal level, but also for ACT UP, I would – I certainly wasn’t the only one, but got in touch with the companies, found out what I could about what was going on with the companies. Protested.

**SS:** Can you detail a specific interaction with a specific drug company that you had around compassionate use?

**AD:** Well, for example, one of times that Kiki went into the hospital, he was saying he wanted to do an action. And, I remember one of the actions was we called the drug company and said, if you don’t make this drug available, we’re going to go on national television and tell them that it’s not available and this person is dying of AIDS in the hospital, and they agreed to have a meeting and have him talk about what his needs were. And so, it was part of what ACT UP was doing. There were different committees
that were doing it. But on a personal level, as a journalist, it’s easy to get access – to call someone up and say. And so, I felt like, for me, it was calling up John’s doctor, or calling up Kiki’s doctor and saying, this is what I found out about this drug, this is how it works.

**SS:** Do you remember which company?

**AD:** Who was doing Doxol at first? Schering Plough maybe? These were smaller drug companies. There were when things were not yet bought to the point. They were just investigational drugs. Sometimes they would be university scientists who were developing something that seemed to work.

**SS:** So, you would call up Schering Plough and threaten them?

**AD:** Yeah, and say, you know, I’d like to see your clinical data. I’m writing an article. And then they would supply it and then you could give that to ACT UP. But then, you could also talk to the company themselves or the doctor and say, this person really needs this drug. And it was very painful. I mean, Kiki wasn’t able to get the KS drug for a long time, but he was one of the first people to get it eventually.

**SS:** What was the drug?

**AD:** I think he got Doxol. I remember it was very painful for John, who wasn’t getting what he needed. That was also true with Gancyclovir – oral Gancyclovir. My friend John went blind and at the time, I think that oral Gancyclovir wasn’t yet quite available when he was going blind and it’s very intense when you know that something is emerging, but isn’t quite there. And, for the most part, I felt like they were actually still privileged, in the sense that they were the first wave of people who even were able to get access to those drugs – to try that. Those drugs weren’t necessarily being used in the
right dose yet. They weren’t necessarily always drugs that worked, but they tried. They
got to try a lot of them. So, I feel like John got to try drugs that other people never even
got a chance to try. Unfortunately, some of them were too late – something to keep him
from having CMV retinitis.

SS: Can we just say that we remember the name of the schoolteacher. BC [Craig].

AD: BC, right. I think she was doing media.

SS: Okay. When did you start working at Out Magazine?

AD: When it began.

SS: What year was that?

AD: I don’t know. I’m trying to think about the chronology of things. There
was NYQ and then there was Outweek. And so, both of those were publications where I
was involved in ACT UP, and I was doing some journalism, covering ACT UP activities,
as well. And from there, was the sort of step to Out Magazine. I think – how many years
was Out Magazine published? It closed in 2000, so it probably was started in 1998
[1992] or something like that?

SS: Well, it didn’t close. It still exists.

AD: Well, it closed as it was.

SS: It changed.

AD: It changed.

SS: Okay, so you think that you came into Out around ’98?

AD: I think that’s when it started.

SS: And what was your position there?
AD:  I started out as a senior editor, in charge of health issues, AIDS coverage and then just general political coverage.

SS:  What was the relationship between ACT UP and Out?

AD:  I think that there wasn’t a formal relationship. There were simply some people who were politically active in or around AIDS who either wrote for the publication or, like me, edited and wrote.

SS:  Did you feel that ACT UP liked Out Magazine?

AD:  I don’t know. I would think that – I would say that the relationship was, that we provided coverage of issues in a way that was reflective of the organization’s activities. Like, I think in the first or the second issue, I wrote a piece about Joe Sonnabend. Joe Sonnabend had been someone who had worked with Michael Callen and some other people very early on. It was, at that point it was almost a historical piece I was writing about. Here’s this person who helped to sort of coin the term “safe sex” and talked about the bathhouse issue.

So, I feel like ACT UP was covered in those ways, by the magazine, primarily because of my position being an editor there and assigning those and also Sarah Pettit and Michael Goff – there were young gay men and lesbians who were, I think, respectful and appreciative of what ACT UP was doing. On the other hand, I think that Out was always perceived as a glossy and ultimately apolitical, in that sense, a media organ and it wasn’t an activist magazine the way that NYQ or Outweek were really seen as community publications. It was the step from a community publication to sort of a national magazine with a different kind of profile. And, ultimately, I think its focus wasn’t necessarily aimed back at the smaller or the gay and lesbian community in the sense of gay or lesbian
liberation. It was trying to be a magazine that had an impact on the greater culture. And, I think it wanted to be a mouthpiece for that community to the greater culture. So, it’s a different position.

SS: And what was the relationship between ACT UP and the Village Voice?

AD: Well. I don’t think I can speak – my relationship with the Voice was just sometimes doing things for them as a journalist. But, I think that the Village Voice has always been a more progressive publication in the sense of covering political issues from a social justice perspective, and I think that it does metropolitan reporting, compared to something like Out Magazine, which is a national magazine. It’s not doing metropolitan reporting.

So, I think that the Voice covered a lot of early things. I think having Richard Goldstein there, allowed a fair amount of coverage of gay issues, gay men’s issues, the bathhouse issue was covered. Some of the protests, specific to particular political people, issues around the Christian right, those things were covered.

SS: Did you write for the Voice?

AD: Just articles.

SS: Who was your editor there? Was it Robert Massa or was it Richard Goldstein?


SS: Did you find that he was sympathetic?

AD: Yeah, yeah.

SS: Do you remember what you wrote about for the Voice?
AD: I don’t think I wrote about AIDS for the *Village Voice*. I wrote about Haiti. Yeah, I didn’t cover AIDS. I covered ACT UP stuff for *The Nation*.

SS: And how was *The Nation’s* coverage of AIDS?

AD: Well, I felt that it was always very, very paltry. And, I felt that they were receptive when I came to offer them something to do. But, I always really felt frustrated, and I think that a million people told them that they needed to get on board and do regular and better coverage and I think that their coverage reflected who was really their staff. And they were not primarily gay men or lesbians, and they weren’t people who were involved in gay and lesbian issues. So, they weren’t really people who were going to be in and around ACT UP. I think they were a more broader, lefty political group.

SS: So, was your coverage for *The Nation* – did it have gay content? Or, was it mostly Haitian?

AD: I remember writing about this meeting that Larry Kramer organized in Washington. It was sort of an AIDS treatment activist coalition. So, I wrote about that and the issue of access to drugs, at a pretty early point, and pricing issues and *The Nation* ran that kind of piece. So, it was sporadic. It would just be whenever something came up that – I remember helping them with – was it an AIDS issue or a gay issue – one of the two, that Sarah and I worked on – Sarah Pettit and I worked on for *The Nation*. And, it was the feeling of doing something that you felt that they should have been doing regularly – not as a special issue.

SS: Okay. Now, you’re also a fiction writer and you published a novel. What year was that?

SS: And it was called?

AD: Under the Bone.

SS: Now, what about the other fiction writers inside ACT UP, were there relationships between them?

AD: I don’t really think so. I mean, there might have been, but not with me.

SS: Who were they, do you remember?

AD: Well, I think, David Feinberg, Darrell Yates Rist, eventually, later on, Dale Peck. Certainly, Michael Cunningham. Michael and I got to know each other through ACT UP and have been in jail together. He’s someone who I feel – the same thing – I’m trying to think of other writers that I know of. Well, certainly, Esther Kaplan is a writer. I don’t know if she’s writing fiction.

SS: Was there any kind of acknowledgement about that or –

AD: I don’t think it’s something that we really talk about – our fiction so much. I think we talked about journalism because we had, if anything, I think that I always felt that my role – one clear role for myself in the framework of AIDS was being able to provide information, and being able to take the information and what was happening in the community around me and make it available to a greater world and vice versa. So, I could take the world of science and make it available to consumers, or people who didn’t have any educational background to understand science. And, I could also write about what was happening at an ACT UP meeting or give some coverage to the issue, to the community that would then be for a broader, progressive community. I rarely wrote for really big mainstream publications about AIDS – once in awhile, but I really wrote about
Haiti more for those – the bigger – *Washington Post* and those places. That was my Haiti coverage. I didn’t really write about AIDS for them.

**SS:** Okay. Now, a lot of people, for a lot of people, ACT UP was a place for – where they made friends, where they found lovers. There was a lot of social life. And certainly, you had quite a few girlfriends in ACT UP over time. How would that – if you were willing to say, who were some of the people you went out with and how did that impact on what subjects you got involved with?

**AD:** Well, I don’t think it’s appropriate to name them without having checked with them first. Some of them, I don’t know that they’re identified as lesbians.

**SS:** Well, then let’s call them Madame X or whatever – but, how did your sexual relationships with other women in ACT UP lead you to certain areas of interest?

**AD:** One of my great loves was a woman I met at an ACT UP conference – at an AIDS conference. And, it was, very much, in and around ACT UP activities. I form very deep friendships. So, I think, in that way, definitely ACT UP was a place for people who I found interesting.

They definitely came together there and I made friends with him there. I think that for the women who came into ACT UP, it’s interesting to me that I think I was primarily involved with women who have ended up being with men. I’m not sure what that really means. But, I think it means that a number of women were drawn to ACT UP because they were really drawn to the kind of energy that gay men brought to organizing and the sexuality that gay men have. I think that they felt very comfortable in that, and
that’s a lot of young lesbians that I was around. It was certainly true for me. And, I think that it sort of facilitated being able to –

SS: But, how did it bring you to projects? I remember one girl that you went out with who was very involved in treatment. Did that bring you closer to treatment issues?

AD: No, I think that we got involved because I was involved in treatment, because I was already writing, so we naturally spent time together and became lovers for awhile. I think it’s that great sense of connection that you get when you’re urgently involved in an issue when you’re working and your work is your pleasure and somebody else feels the same way. I mean, they’re very passionate relationships because you care so much about what you’re doing.

SS: What was the lesbian sub-culture of ACT UP like?

AD: You know, I don’t know that there was a lesbian sub-culture. There weren’t as many – there were a lot less women there. But, I think that if anything – what I really felt was that it was a sub-culture that reflected sort of a generational shift of lesbians who were active in the world as open lesbians, who felt very comfortable in their sexuality, who felt – they didn’t feel defensive in their sexuality, and they also were very open to forming really intimate relationships with gay men, and they weren’t necessarily defining themselves as bi-sexual either, but they were really actively taking on a political and sexual identity, as lesbians, that I think was something that a lot of other lesbians were doing – not in the context of AIDS or ACT UP. So, it was kind of a convergence of those two things, and I think that it allowed a lot of lesbians to go on from that kind of organizing and to become – develop a level of skill and a level of awareness that they
then went on to do in other groups, like the Lesbian Avengers or Queer Nation or things – but, as lesbians. And, for many of them – to get really involved in establishing institutions around AIDS. I mean, there are so many people who have gone through ACT UP who are lesbians who have taken critical roles in this epidemic.

SS: Like who?

AD: I can think of – a list. Amber Hollibaugh, Lesbian AIDS Project.

SS: But she was never in ACT UP.

AD: Well, she was in ACT UP until she felt it wasn’t focusing enough on lesbian issues, but she went through the ACT UP umbrella early on.

SS: Really?

AD: Mmm hmm. Oh gosh, names. I’ll just say the organizations.

SS: Okay.

AD: The New Jersey Women and AIDS Network –

SS: Marion Banzhaf.

AD: Marion. Jennifer, who’s doing the New York Housing Network. Nina Herzog, who got involved in establishing Housing Works. There’s a long list there.

And, I know people who are working in prison issues – really, lesbians have been so active on prison issues. Lesbians were active on needle exchange issues. I just feel like they were active on women’s issues. When I think about what’s happened in terms of women and HIV, it was the lesbians and the women who did that. It wasn’t the men in ACT UP. And, had the men gotten involved, it would have made a tremendous impact. Because we really needed more numbers, and so much more to happen.

SS: Were you involved in that campaign?
AD: I was involved, sort of – I would say – in the second and later stage. By the time I got involved, I think already, the first Women and AIDS handbook had been written by the women’s committee.

SS: So, you’re one of the five founders of the Lesbian Avengers and that was 1993. What was it about ACT UP that made you decide to start the Lesbian Avengers?

AD: Well, I think that – first of all, it was some of the experiences of friendships within ACT UP, and the watching the style of activism. Getting to know people like Maxine [Wolfe] and you – and feeling, I think that, at that point in the epidemic, that lesbians had been so actively involved and what was happening in the city at the time was that – I think – there just was very little visibility that was being given to lesbian issues on a national level, on a city level. And, I think it had to do with that generational shift that I was talking about, where you had women coming in who sort of had energy and brains and felt really strongly about the need for more visibility and attention to lesbian issues. And, there was also, I think, the sense of play that had emerged that has to do with the social aspect, also, of activism. And, I think it made activism more appealing to people. And, so I think that all the ingredients were there for women to say, we really want to hang out together, we want to do something, and we really need to speak out more.

I think that time, also, was driven partly – it was partly in reaction to a climate of sort of, really right wing activity on the part of the Christian right. And so much attention had gone to AIDS issues that I think that less of it was going to gay and lesbians specifically. And again, when it was being addressed, it was being addressed to the way
it related to gay men, and not to lesbians. And, so I think it was very natural for the Avengers to find that they had an issue around which they could speak that wasn’t just broad, lesbian visibility that allowed some organizing to happen.

SS: Okay, now you stayed in HIV all these years. Why do you think that is?

AD: I think that there are two reasons. One is, I have a brother who’s HIV positive and I feel very invested in keeping him alive. And, he is someone who became positive not very long ago. So, it was really at a point where I was sort of thinking about the idea, could one ever retire from AIDS when AIDS wasn’t over. But, I was very tired and had thoughts about trying to see if I could shift to journalism that might be broader and be beyond AIDS. And, I was very fatigued emotionally from caretaking one of my closest friends who died, because I was one of the main caretakers for two or three years, and that was an exhausting period of time.

SS: Who was that?

AD: John Cook. So, it’s John right after Kiki. And, there were some folks that I had known in Paris. I was really close to ACT UP Paris. One of my girlfriends was in ACT UP Paris. I was very involved in ACT UP’s activities. And, what I found was that, as I was getting tired, and there was a lot of burn-out happening in New York, that ACT UP Paris was taking off, and a lot of the energy and the enthusiasm and sense of possibility that had really driven ACT UP here in New York, was found there again. So, I got re-inspired by the activism of people in Paris and I think that they were also beginning to look globally and focus on what was happening in French-speaking Africa. And so, it was kind of going back to my roots. I started to reconnect with people who I
had been doing work with earlier on human rights and things like that. So, it sort of got me staying in there.

**SS:** What are you doing now?

**AD:** Now, I’m very involved. I’m doing, essentially – I’m continuing to document and investigate the – what I consider to be the frontlines of AIDS work – in terms of access to treatment in developing countries. So, I’m doing three things. I started, a year ago, writing a series of articles for a medical newsletter that’s published by the American Foundation for AIDS Research, to look at what are the challenges of implementing HIV therapy in settings of extreme poverty, and my goal was to try and identify things that worked. And I think that’s informed by ACT UP and activism – is trying to see what works and how can this model be applied elsewhere. At the same time, you document what’s not happening, but I was really more interested in the solutions and in identifying people who were potential activists.

And so, I’ve been making friendships and new connections around the world, and feeling like I have a lot to share with my experience that people are very hungry for, in these other places. I have also – so I’m doing that, and putting that together for a book, that’s going to come out in time for Bangkok, hopefully.

I also got involved in documenting the history, through a movie – making a movie about the global AIDS movement. That started about two or three years ago. I felt that I hadn’t been thinking at the time of ACT UP to document things then, and I realized that it was really imperative to do it, because it could serve as a tool now, to motivate people and to educate them around treatment and access.
But, also, as an opportunity to reflect on what this second wave of activism, as I think of it, could maybe – what it was taking from the first wave of activism, but also, what maybe the differences were between global AIDS activism, and the kind of activism that had developed here, domestically, because I feel like the face of activism in the United States and Western Europe is very different from global AIDS activism. And so, I find it very interesting to think about.

SS: What will have to happen – I guess this is my last question, really, but

AD: You want to hear the third thing?

SS: Oh, go ahead, sorry.

AD: Well, the third thing is something that I’m daunted by, but I feel it will open a new chapter for me, if it happens, which is that, I’ve just gotten involved in proposing to an organization that is going to be working in Rwanda, that they consider a treatment project and a research project for 250,000 women, who were raped in the civil war in Rwanda and all are positive. And, the idea would be, not only ethically, to provide them with treatment, but to think about building in a research component so that we can learn about what’s going to happen with all these women who go on treatment around the world, and that they can be involved in setting that agenda, because that’s something that we did here in the United States. It was HIV-positive women who did it here, but it started late here, and we missed an opportunity to get a lot of information. A lot of women died or suffered in ways that they didn’t have – shouldn’t have. So, I’m thinking of trying to apply what we learned here. And so, the women, for example, of WIHS is one of the sort of big cohorts that got established here. I’ve just been in touch
with them and saying, would you consider, would you be interested in trying to see how to work in this setting? And, they’re very interested. So, we’re going to meeting and having those meetings next month.

SS: **What’s the organization?**

AD: Well, in the United States, it’s the Women’s Interagency HIV Study – WIHS – some of the leading researchers who work on women and HIV issues, but it taps into the whole system that was set up – the whole networks that were set up here, to look at women and HIV and these very nascent organizations of women in Rwanda, who are trying to keep themselves alive.

SS: **And have you been there?**

AD: I haven’t been to Rwanda yet. I’ve been in communication with the women, but I have been going and working very actively in Durban and South Africa. Two years ago, I worked there, and then, last year, in Uganda. So, I think that I’m moving –

SS: **This is for AmFAR?**

AD: No, it was just on a personal level – working with – trying to provide access to education and treatment to positive women.

SS: **This is my final question for you, Anne – concretely, what would you say would have to happen for there to be global access to the meds that we now have available in the U.S.?**

AD: There would have to be political will that doesn’t exist yet, to provide that medicine free and set up systems of delivery where it somehow was provided as a general public health service and not specifically to these people who are being identified in these
particular mechanisms because of the stigma. I think, with the stigma, it’s going to be a really long time for people to get access because it’s too difficult, it’s too dangerous, it’s too challenging for them, to always be able to figure out how to identify those resources even when they’re there right now. And too much – it’s going to take so long to change this intense cultural and social hurdles.

So, I think that there will eventually be access, but I’m afraid that it’s going to reflect the degrees of access that exist for people with other kinds of diseases or resources. Although, I have to say, I have been impressed by the revolutionary potential that has been manifested in the AIDS arena, around access to medicines. And, so many, sort of, I guess – I would almost think of them as sort of – so many mountains have sort of fallen, have sort of revealed themselves to kind of be paper mountains or paper tigers – things that were unassailable. That fell because of, more than anything else, the moral rightness of the issue. So, I would say that there is the possibility for seeing something in the AIDS arena that we haven’t seen in other arenas, that this will cause major shifts. But, the scale is incredible and the speed of the epidemic is incredible, and so many more people need to be involved, and I think they’re getting involved.

For years in ACT UP, we would talk about international issues, and the people who were talking about that were the people who were from those countries – the Latin American activists, the people who lived in Diaspora communities in the United States, Haiti – and it just wasn’t seen as an issue for ACT UP, at the time, and so it feels like – I’m glad it’s happening now, but I just wish there had been a way to be able to go back and have that kind of activity happen a few years back, because so much more could have been done.
SS: OK. Thank you.

[END OF INTERVIEW]