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Interviewee: **George Carter**

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Interviewer: **Sarah Schulman**

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SARAH SCHULMAN: Okay, so the way we start is if you could say your name, your age, today's date, and where we are.

GEORGE CARTER: My name is George Carter. I'm – oh, god, my age? My name is George Carter. I'm 46 years old; be 47 shortly. And we're at the apartment of James Wentzy. And I believe it's April 16th, 2007.

SS: Okay. Nice to see you, George.

GC: Good to see you, too. Three.

SS: So I don't even know where you grew up, or anything. Where were you born?

GC: I grew up in western Pennsylvania, in a little town called Greensburg, about 25 miles east of Pittsburgh. And I lived there till about 1980; moved to California; lived there for about four years, in San Francisco, mostly; a little town –

SS: Wait. How old were you when you left?

GC: About 19, 20.

SS: Okay. So it wasn't like your family moved away; you left.

GC: No. You're right.

SS: So you lived your first 19 years in Greenburg –

GC: Greensburg.

SS: Greensburg, Pennsylvania.

GC: Right. Mostly. I lived in Pittsburgh, where I went to Carnegie Mellon for a couple of years, until they managed to lose my financial aid. And so in my junior year, I received a letter saying, you owe us sixteen, twenty thousand dollars, whatever it was. And I was a little taken aback. And –

SS: Is Greensburg like a small town, or is it like a suburb?

GC: Small town. No. It's practically a suburb at this point. It's become, I guess you could almost call it a bedroom community of Pittsburgh. But at that point it was still its own small town. And I actually grew up in an even smaller municipality of Greensburg, called Southwest Greensburg.

SS: So would you guys go into Pittsburgh a lot, or –

GC: Yeah.

SS: Like twice a year, or –

GC: Oh no, like maybe once a week, or once every other week; something like that. Pittsburgh was the big deal.

SS: Okay. So you said Southwest Greensburg.

GC: Right.

SS: So what did your parents do?

GC: My dad worked in a bank. My ma was, is a very marvelous and strange woman, who, very, very well read, plays piano, did the housewife routine, got her masters in library science, and became a librarian in different places, worked different jobs. They got divorced when I was 12.

SS: Okay.

GC: And – yeah.

SS: And who did you live with?

GC: I lived with my mom.

SS: Okay. So was your mother, so she wasn't a librarian yet, when you were a kid.

GC: When I was a kid, no. She was basically there for us.

SS: So were there a lot of books in your house, growing up?

GC: Tons.

SS: Tons.

GC: Tons of books and music, and she would do wild things, like make Chinese food or Indian food, in her own inimitable style. And I grew up listening to music from Yugoslavia, Russia, Armenia, and classic music; always had music in my life. She played piano, and the virginal.

SS: And how did she get into the world? I mean, where did all that come from? Was she from that area, or –

GC: Yes, she grew up in that area. Her parents lived around the block, so they were very much a part of my life, my grandparents. And my granddad was also in the bank. His family came, were coal miners that came over from England. Well, actually, his family had been there for generations. My grandmother's family had come over as, she was the first generation.

SS: And where do you think she got this wish, or interest, in the big world?

GC: I think it's just the peculiarity of being English in a world that was not full of so many English people, perhaps. It was just her nature. She was always curious and interested in things. And loved gypsies and foreign and unusual places when she was a kid. She was always fascinated by those kinds of things.

SS: So did she give you piano lessons, and –

GC: No, she just asked me and my brother what we would like to play, if we'd like to play an instrument. And I said immediately, violin. And so I've been playing ever since.

SS: Oh, really?

GC: Um hm.

SS: Oh, that's cool.

GC: Yeah. In fact, I was just playing in a string quartet yesterday afternoon.

SS: And did she read to you when you were little?

GC: Yeah.

SS: Do you remember books?

GC: Sure. She read *The Hobbit*; she read [Edith] Nesbit's books – Samead; and *The Moomintrolls, The Finn Family Moomintrolls* books; they were great.

SS: So were either of your parents involved in any kind of community organizations or church or PTA, or anything like that?

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00:05:00

GC: Not at first. My father was, but I was not particularly interested in any of that. And to be honest, I don't recall exactly what it was. It was maybe some kind of block association.

Later in her life, my mom became, well, spearheaded and produced the tree commission. And I think it was partly because of my activism, she realized she could be an activist. And so she tried to get trees planted in her community, because they'd been busily cutting so many down.

SS: But you weren't raised with any kind of ethos about –

GC: Not particularly, no.

SS: – community.

GC: No. To the extent that the world community always fascinated me. Since I was a little kid, I was always, partly by that influence of my mum. I found my own things that intrigued and in-, that I embraced. I loved Prokofiev when I was like five or six years old. The *Love for Three Oranges Suite* was one of my favorite pieces when I was little kid.

SS: So how did that sit with the other kids? Did it connect you to them, or –

GC: I, yoof. That's, partly was the be-, the beginning of my feeling like an outsider. I have always, always, always felt like an outsider. I have never belonged to any community, in a very odd way. I always knew I was gay; I always knew I was queer. When, later in life, I tried to commit suicide, it wasn't because I was queer; it was because I was living in a world that hated me for what I was. It was a rather feeble attempt, obviously, or I wouldn't be here. But I always felt strange.

And it was highlighted, in a peculiar way, by a kid — I think maybe about third grade — turned around and said, are you from England?

And I looked at him, startled. I said, no, I grew up down the block!

But part of that, I think, arose from the fact that I, I looked a little different. There weren't a lot of blond-haired, blue-eyed kids in my community. Some. Certainly there was a lot more white people there. I mean, it's basically white. But a lot of Eastern Europeans, Hungarians, Czechs, Slavs, Slovaks, Poles.

SS: Andy Warhol's people.

GC: Yeah, sure. Absolutely. That was, that was western Pennsylvania. And western Pennsylvania has a very peculiar regional accent, that's specific to that area. I can't even do it very well. But, {IN ACCENT} you know, you, youn's want to go dahntahnn, and have some beers.

And then I lose it; I can't even keep it.

SS: So what do you think was more alienating; the interest in the big world, and these cultivated tastes that you developed, or being gay? In relation to the other kids.

GC: Neither. I think it was more just being smart.

SS: Being smart.

GC: Yeah.

SS: So when did you start making plans for your escape?

GC: I didn't. Really, particularly. I wasn't really – I was rather propelled into it. In my freshman year of college, my mum met a fellow, and married him. And he lived upstate New York. They wound up living in Peekskill, New York. And so the home I grew up in was sold. And between my freshman and sophomore year, I suddenly was homeless, so to speak. So I wound up staying in Pittsburgh, and wound up joining a rock and roll, pop-punk band called The Rave-Ups. Which was a really marvelous experience. Of course I was deeply in love with the lead singer, who of course did not return that love.

SS: Oh, that's sad.

GC: Story of my life. But it was still a fascinating experience, and a fascinating period of time for new music. This is late '70s, early '80s, when all these, all

the good new stuff that was coming out was coming out of little towns like Pittsburgh and Athens, Georgia and Cleveland; places like that. It wasn't coming so much out of New York or London or L.A.

SS: And this was while you were at Carnegie Mellon?

GC: Um hm.

SS: And were you out, at that time?

GC: Yes.

SS: And what did it mean to you, to be out, at that time? How did you manifest as a gay man?

GC: {GIGGLE} Well, that's a funny s-, when I, I had actually already come out in high school; first to my mum. And I'll never forget the conversation. We talked about, gee, I have something to tell ya, Ma. She, well, what is it? Are you sick?

No no no, I'm okay, no, I'm not sick.

Are you doin' drugs? You know I'm doin' drugs.

She did.

And says, well what is it?

She looked at me, she says, and, given that she reads a little too much, she says, are you in love with me?

I said, no, I'm gay!

And she laughed, and she says, oh, that's all?!

And I also came out then to friends that I was with. The friends that I was developing in high school were the kids that did the drugs. And they weren't necessarily the smart kids that were in the calculus class that I was also in; that I liked, I mean I got

along fine with them. But they weren't very interesting to me. They were kind of very suburban, normal kids, and they kind of bored me.

Then I found this whole set of kids who had long hair and smoked pot and dropped acid; actually, I was the one that dropped acid, and brought that to them. But anyway –

They were a lot more interesting, because they played guitar, they sang songs, they read Tolkien. We had just great times together. So that by the time college rolled around, I thought, well, "All in the Family" already did a segment where they had a drag queen on, and they've had gay people, so, you know, they've dealt with racism and homophobia. It's okay now; everybody's cool with it that has a half a brain. And the rest are just brain-dead idiots anyway, so who cares?

So one night, I was with my crew of friends; they were another great crew of crazy friends I'd made at college, in freshman year. And sitting there, kind of drunk, with a bottle of vodka on the turntable, turning. And we were talking about world issues and politics. And I said, you know, and racism and all that kind of crap. Why do people get bent out of shape over what somebody is? I mean, I'm gay, and who the hell cares?

And there was a sort of dead silence in the room. And I looked up, and realized that they were all just sitting there, like with their mouths gaping open, going, whaa?

And then my, a friend of mine, Scott, just started laughing like hell.

At that point, I think people began to think I was faking it. Because in this band I was in, there was a friend of mine — who's still a very, one of my closest friends, ever — everyone thought he was the gay one and I was making it up. But he's –

SS: But did you have any gay people to hang with?

GC: Um hm. Yeah, one of, a friend of mine was a first lover.

SS: And that's in Pittsburgh, or –

GC: Pittsburgh. Yeah. At Carnegie Mellon.

SS: So was there like a gay scene at Carnegie Mellon?

GC: Nah. The scene at that point was probably the last scene before the calculator set came into town. And they kind of cleaned up their act at the school, and seemed to have less interest in anyone that had a kind of alternative lifestyle. My freshman year, we had some of the most, it was a marvelous crew of people, because they were artists, they were architects; engineers, chemical engineers, electrical engineers; actors; people like, and I was in, psychobiology was what I was trying to major in. And it was a – a very wild bunch. We drank a lot, we did a lot of drugs, we had a helluva good time. And we also worked a lot, in school. But it was the last big real crowd of independent-minded people. After that, it seemed to become more and more Reaganesque. It was more and more straight and narrow. The pens and the calculator on the belt, kind of –

SS: Were you into politics at all? I mean, beyond the theoretical?

GC: Only to the extent that when Ronald Reagan was coming into office, I was aghast; kind of startled by this whole bizarre notion that the sidekick to a monkey was now going to be the president of the United States, and he was this right-wing extremist, and I was thinking, now how the hell do I get out of this country?

So I was politically aware, to that extent; but really, not deeply.

SS: Okay. Did you give up on psychobiology, or did you intend to continue with that?

GC: Well, like I say, it kind of gave up on me, because junior year, when I was really beginning to get into the course work, I got this letter, so I took a leave of absence. And at the same time, the band I was in got a call to go to Los Angeles. So we went to Los Angeles and did a couple of gigs. And that was quite a lot of fun.

And at the same time, the department evaporated. They had four professors who were involved in this study of the structure and function of the brain, and pharmacological methods to alter it. I mean, quite honestly, my interest was to try to figure out something better than LSD; or something as intriguing or engaging. Because for me, drug use, even though it was a sop to pain — which I knew — it was also a spiritual awakening and exploration for me. It was trying to figure out, you know, what the hell is this thing called life? What are these experiences that are available to one? What are these people that do this kind of thing?

So – because they had dissolved the department, there wasn't any point in going back to Carnegie Mellon. And at that point, within a year or so of that, we kind of moved to California, the band more or less broke up — I think in part because I was gay —

SS: Really.

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GC: Yeah. Because there was a producer who was very interested in this one fellow in the band. And the other fellow, who's still my friend, but didn't really like me, because I was an out gay man, which is like – just kind of stupid. I mean, just from a, from a business perspective; I'm not talking about even just the ethics of homophobia;

that's obviously grisly. But you could make money on that. That he couldn't see that, but he had this very narrow, L.A. attitude.

So I wound up moving to San Francisco and becoming kind of a performance artist and junkie.

SS: Now how did that happen? Where were you living in San Francisco?

GC: Lived, well, I started out living, I was homeless for a while. Stayed with a friend sometimes; sometimes on the street. But mostly, then I got into the Leland Hotel.

SS: Is that in the Tenderloin?

GC: No, it's on Polk Street.

SS: Okay.

GC: That was a trip. That was a place where you woke up in the morning hearing about the body found stuffed between the mattresses; people routinely dying of overdoses.

SS: Just really honestly, why do think you ended up there?

GC: Because it was beautiful and I'm queer and my god; are you kidding me? L.A. sucked.

SS: No, being a junkie and living in a place like that.

GC: In the Leland Hotel?

SS: Yeah.

GC: It was cheap. What are you looking for?

SS: No, I'm asking, like, why do you think you ended up being a junkie in San Francisco?

GC: Um, because it was a, it was sort of the last frontier of drugs that I was curious about. And the first time that somebody injected me, it was a guy who was – turned out to be a very gorgeous drag queen. I remember looking at a picture and saying, is that your sister? He says, no, that's me. I said, you're kidding.

And we had some great sex. And he had shot me up with some drugs. And that was it {FINGER SNAP}. I was interested in it; wanted to try it.

And I thought, I knew it was a risky thing to do. I figured I'd probably be into it for a couple of years, because it kind of shed a lot of the other drugs I had been using, as having not been all that interesting. But the junkie, people that did heroin were interesting to me. I loved Lou Reed and, even though he never was, but that whole mystique of that kind of music, of that head space, of the punk movement that was burgeoning in San Francisco at the time.

I did shoot speed and coke. Hell, I shot LSD once. That was a trip, as it were. But I didn't like speed and coke, because they gave me the most intense depressions, which only heroin seemed to fix.

So I got into it basically because I was intrigued to learn about this underworld, this underbelly of the world. And I began to know the people in it, and learn to love them; because they're people, and they're marvelous, and they were smart; sometimes very brilliant people; sometimes paranoid, sometimes, just any kind of walk of life, but they were thrown together, and altogether kind of outsiders in their own way. And again, it goes back to feeling like an outsider.

So even though I was involved as a heroin user, and went to the On Broadway and Mabuhay Gardens and Tool and Die and all these places where bands like Black Flag and the Fuckups played and all that kind of thing; and hanging out with the sex workers on Polk Street, and kind of mentoring them, actually. I mean, I was the old kid because I was 21 at the time, at that point. I listened to them, I listened to their stories. And they never had anyone that did that before. And I wasn't interested in them sexually. I mean, it just wasn't my type.

So – I just wanted to know what those people were like. And I found that like people, in many ways, they had certain senses of, or certain conventions. So there was a conventionality to being a heroin user. And ultimately, that's what got me off it, because it simply became boring. It took about eight years, though.

SS: So which years are those?

GC: [19]81 to '89.

SS: Okay, so those are the AIDS years.

GC: Yes, they are.

SS: So okay, let's start in '81. So you're in San Francisco. You're gay; you're doing heroin; you're hanging out with hustlers. When do you first hear about AIDS?

GC: Intimations around '82, probably; that there was this disease that was killing people. Seemed like it was Los Angeles, so that was far away.

SS: Do you remember a specific moment or person?

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GC: Not really, because it wasn't till I moved, I moved to New York in '84. And it wasn't till afterward that I realized that two of my roommates that I lived

with — because I lived for a little while in the Leland Hotel, but the majority of my time then, I wound up living South of Market, on 8th and Howard.

And that was a great bunch. There was a fellow there who was in a band. He was a very brilliant fellow. Always used to say, never use my works. We didn't call it works, though. We called it point, or rig, in San Francisco. Works is a New York term for the syringe.

And of course one time, I had been using the same syringe over and over, and it was turning into a nail, so I snuck into his room and pulled it out and used it. Cleaned it first. I was also very, I wasn't concerned about HIV, although I was aware of it, yeah, as I think about it now, there was increasing awareness by that time, that I was living there. And so I always cleaned it with, just with rubbing alcohol.

Turned out that Paul had HIV and he died of AIDS, probably 1988. And he was the first heterosexual that I knew that had AIDS. Marvelous, brilliant, sometimes obnoxious guy. He had his obnoxious side to him. But there was always a good humor about it.

SS: So when you were still in San Francisco, from '81 to '84, it wasn't in your immediate world.

GC: Not that I was aware of. I wasn't aware to what degree it was.

SS: So what made you move to New York?

GC: I wanted to stop heroin.

SS: Did it work?

GC: No. {LAUGHS} It was a bit of a joke at the time, too. I mean, we were –

SS: You moved to the Lower East Side of Manhattan –

GC: You bet.

SS: – to get off dope?

GC: Yep.

SS: {LAUGHS}

GC: And that was where I wound up OD'ing; nineteen-eight –

SS: In your apartment?

GC: Yep. I was living on 4th between A and B, with a couple of women; one who was a film director – I think she still is. In fact, she still lives in the same apartment.

SS: Now who's that?

GC: Mary Bellis.

SS: Don't know.

GC: She's a trip. She's a total trip. Canadian woman. And Mary Bolger, who I think is now living in San Francisco, and last I heard, she was channeling spirits; stuff like that. But she was great. And they loved me and I loved them, and we got along. And I lived in a room that reminded me of Andy Warhol's *Trash* for some reason. It was entirely painted black, including the windows; floor, ceiling, walls, window, black, mattress. That was it.

SS: Can we just make a historical point here, that in 1984, East 4th Street between A and B was filled with people yelling out the brands of heroin that they were selling? And you could probably hear it from your bedroom, right?

GC: I was mugged by kids that were doing it.

SS: Oh, okay.

GC: Yeah. Oh yeah, no, I knew, and – yes. It didn't stop me. In fact, I remember, at one point – the night I OD'd, I hadn't done any for a couple of months. I had enough heroin to get across the country, because some friends drove me across; took a couple of weeks. And we got stuck in the middle of Wyoming. The van died. And I'll never forget, hitting up and just, we finally realized we weren't going anywhere. And just sort of saying, well, fuck it. And banging up some dope and watching the stars. And it was beautiful. And we wound up getting along, that's another story, but –

The night that I finally, it was a few months after I had moved to New York. And I had copped some dope from an old friend, who I had visited a couple of times before I moved there, moved here. And I remember very distinctly putting some dope in the spoon; this brown dope, a little lemon juice. Fixing it up. And then I remember just shooting it; putting everything away; and getting up and going out. And then going to a bunch of different art galleries and nightclubs. And these were quite distinct memories that I had. Then I remember kind of walking around the apartment, not being able to see, and drinking lots of water; and throwing up. And then we took another walk.

And the last thing I remember was listening to the Tchaikovsky violin concerto. And it was the most glorious thing I'd ever heard in my life. It just filled me with such ecstatic joy.

So the next morning, I wake up. And another friend of, I'm the first one to wake up, as is kind of often the case. My friend Andrea wakes up, and I say, hey,

where did we go last night? I mean, I kind of knew, the East Village, but none of those places looked familiar.

She looked at me. She says, what the fuck do you mean?

I said, where did we go?

She said, you didn't go anywhere.

What do you mean?

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00:25:00

We had to kick down the door; you were blue. You were dead.

And my friend Michael, who was in the band, who everyone thought was gay, was living nearby, and came by. And we had done this before, numerous time, with many friends who had OD'd, and we just got them up and going and moving around, and made sure that they weren't going to die. And kept them alive. I did know people who'd, they'd, others did not do that for. A friend of mine, Crawford, in San Francisco, back in '82, drowned in her own vomit, because nobody gave a shit.

So I guess that was my karmic payback for the other people that I saved, that Michael was there to come and save my ass.

So all that, those events that I remembered — and this was the peculiar and fascinating thing, to me, on a experiential level, about heroin — the kind of hallucinations that are created, or dreams; they're deeper than dreams when they happen. I mean, this would happen to me; I remember nodding out in front of this little black and white TV I had, and watching a movie from the '40s. And the characters would be carrying on, doing things, and I'd suddenly come out of the nod and realize there was a commercial on, and that that last five minutes of movie hadn't happened.

But it's far deeper than a dream, because there seems to be tactile, auditory – it's more like a living reality, in a very odd way, than, say, an acid hallucination, where you are conscious, but it's more visual or auditory or there's synesthesia.

So there was that aspect to my drug use, too. I was also fascinated from the standpoint of experimentation, and what is this doing to the body; what is it doing to the mind; how does this help me understand who I am as this creature that wound up in this body? Why?

SS: But in those four years that you were using in New York — '84 to '88 — did you have a boyfriend?

GC: Yes. I hooked up with my friend Pierre, who – we actually met, I actually fled New York at the end of '84 and lived in London for a few months. And then was doing performance art with the Voluptuous Horror of Karen Black.

SS: Oh, Kembra Pfahler!

GC: Yes! The very same, and Samoa.

SS: You were in the Voluptuous Horror of Karen Black –

GC: Yes.

SS: – with Samoa –

SS: – and all those people?

GC: Yes.

SS: Those are our friends. Yeah.

GC: Oh, cool! Six degrees. Yeah, and then we went, we did gigs in – London. And then we did one in Amsterdam. And they knew Pierre from New York,

and I'd actually meet Pierre at the Avenue A Sushi, had its liquor license party. And that was where I first met him. But they knew Pierre very well. He was a great artist; did these giant puppet shows.

So we stopped in Paris on our way to a gig we were going to do in Madrid. And spent two or three days there. And {FINGER SNAP} Pierre and I hoo-, hit it off. I mean, it was like hand in glove, so to speak.

SS: So what made you get off the drugs?

GC: Boredom. Ah, let's fast forward. Pierre and I did performance art together for a few years. We lived, we moved to Montreal, and I kind of lived there from '87 to '89. And in the last year, I was really over it. I just kind of wanted to stop. And he, unfortunately, was going a different direction, and had met this kind of crazy, marvelous but very fucked up woman, who was an alcoholic and coke addict, and he was starting to shoot coke. And I was begging him; go back to heroin. Please, I'll do heroin with you. Not this; it's making you crazy.

We had a beautiful German shepherd named Sappho, who unfortunately kind of lost her mind. But I finally said, I have got, I can't stay with you, I have to leave. Because you're going to die if you keep doing this. And I'm not helping you, and I'm enabling you, if anything, and I got to go.

So I moved back to New York. Two threads then: one thread, for him; he managed to clean up. And he's, I just got an e-mail from him the other day — no, this morning — he's had his gall bladder out, because he's co-infected with HIV and hepatitis C. He was infected, probably, in the early '90s, with HIV.

So I get back to New York in '89. And I realized that I was done. I had started and stopped a few times over the last few years prior to that. And I kind of trusted myself to say, I know I'll be done with this because I just won't be interested in doing it. It's what happened with other drugs in the past, like LSD. I'd still do LSD if I had found the right set and setting and found some. It's a fascinating drug. But – I don't think New York's the right set or setting, for me.

Tape I
00:30:00

I, okay, the event that I knew I was done was when I'd moved back, I was living on 7th between C and D. And I was walking between 7th and B and C. And at that point, in '89, it was the best heroin in the neighborhood, right there. Really good stuff; I had 10 in my pocket. I thought, well, I can do this. No one'll know. And I'll probably feel a lot because it's been awhile. So I'll get a good nod; I'll feel great. And then I'll kind of feel crappy tomorrow, but probably not too bad, if it's just a bag. But then I'll kind of, maybe I'll want to do it again, and is the nod really worth it, and, ts-, eh, fuck it; I don't really care that much.

And I walked by. And I kind of knew I was done then. And haven't touched it since.

SS: Okay. So it's '89; you're off heroin; you're back in New York. And so now, where is AIDS in relationship to your life?

GC: By that point, I knew so many people from the arts world that had HIV and that had died. From the East Village scene. I was finding out about the New York scene, or, sorry, the San Francisco scene –

SS: Can you tell us some of their names?

GC: Baby Gregor, although he didn't die of AIDS. Huck Snyder.

SS: Yeah, uh huh.

GC: We did performance art with him; my friend John Kelly – you know, the only problem I had with saying these names is John is still alive.

SS: Well, John Kelly is alive, yeah.

GC: He's still alive, right. Gordon, uh –

SS: Kurtti

GC: – yeah. Um – there was – god, see, this is where the hole in my brain comes in.

SS: Is there one person –

GC: Brian Kaup.

SS: – who you remember really being like, oh, this is someone really in my life?

GC: Pierre, but that was later. They were – well, me. I fig-, I had every reason to suspect; I was a needle-using queer. And still queer. I hate to use the word "was" there.

SS: So did you get tested?

GC: Not right away, no. Because there didn't seem to be any point to it.

SS: And were you at all involved with – how are we doing?

James Wentzy: Good.

SS: Okay, so it's like 1990. Do you suspect that you're HIV-positive? Some people who are you colleagues, on some level, have died, or are sick.

GC: Yeah. Friends.

SS: And what made you plug into the AIDS community?

GC: Actually it was '89.

SS: Eighty-nine, okay.

GC: And one of the things I knew about the heroin use was that in transitioning from using heroin to not using heroin, suddenly now there's this void of time. And I'm very grateful for the experience, because the people that I work with now very often are current or former users. So I know what they're going through. And I know one of the things that, when a person's ready to make life-changing choices, like this; again, not because it's illegal, or Mommy says it's no good, or you feel guilty about it, or it's bad for you; those reasons are, I guess, okay, but for me, they're kind of irrelevant. The reason that you want to stop is because you want to stop, and you choose to. Not because of any of the other – they make sense, those reasons are, are okay. But to be driven by guilt is not a very successful way to quit, I don't think. And transitioning requires that you have some kind of a – something to fill the time; something to do with your life. What do you want to do with this life? You have this, if you're not hanging out with the friends, copping dope, waiting to cop, getting high, nodding; working to make enough money to cop, or whatever. So you have all this free time.

I had the violin all throughout my life. So that was kind of a saving grace for me, but it wasn't, I wasn't living on it; and it wasn't the only thing I wanted to do. Well, a friend of mine, Harold Chester, who was in the Media Committee at the time, said, hey, why don't you come to an ACT UP meeting?

And I knew a fellow named Lynn McNeil, who'd had Silence = Death stickers on his door, an apartment in, I think it was Ridge and Stanton – another lovely

place I lived for a little while; also where there was a lot of turf wars for the crack and heroin dealerships. And I was curious about it. And I said, oh, all right, what the hell?

So we went to the Center. {FINGER SNAP} That was it. That was it.

SS: Why? What happened to you?

GC: I went to a room that was filled with hundreds of people who were fighting for their lives, who were the most articulate, compassionate, smart, annoying, marvelous group of crazies I've ever met in my life. One of the people I remember is Garance Franke-Ruta going on up there, at her hundred-mile-an-hour clip from the, giving a T&D report. And I'm sitting there, thinking, what the fuck is PCP? I thought
Tape I
00:35:00 that was a drug? Nineteen eighty-nine. I mean, I knew about pneumonia, but PCP; that was something you smoked, and it made you really fucked up. Angel dust.

SS: Before we get into the ACT UP thing, I just want to ask you one question. Because you're negative now, right?

GC: Yes.

SS: Why do you think you're still negative, after everything you've done? What is your theory?

GC: Heroin. Weirdly. I mean, in San Francisco, when I was on heroin, I was actually celibate for a couple of years; not intentionally, god knows. But heroin was more interesting than men. So that, maybe, and also I'm not as wild – I like sex. I love sex. I think it's great. But I – many of my other friends like sex a lot more than I do. And perhaps that's one of the reasons. It could be a biological thing, that exposure may have been thwarted, if I'm delta 32 homozygous.

SS: That's what I'm asking you, actually; if you believe in that; that there's a biological predisposition.

GC: I think that there can be. Oh yeah, there is, yeah, I do believe in that. I, I think that it's overblown, though, unfortunately. It represents such a tiny fraction of the population. We do know that there are exposed uninfected individuals. But they come from all sorts of different ethnicities. There's the hemophilia cohort in Scotland, the gay men cohort in San Francisco, the Kenyan sex worker cohort. And all of those have members, or individuals, who are persistently exposed but remain seronegative. Delta 32 might explain some tiny fraction of those. And it tends to be more white, northern European, genetic marker, rather than, say, African.

But clearly, there's a lot of ways that people can be exposed to infections and not become infected. What makes HIV, to my mind, so horrific is the fact that the chances, A, of becoming infected productively are much higher than with some diseases — but then again, not as high as, say, hepatitis B — and worse, that once infected, the chances of progressing to AIDS is extremely high; 90 percent of infected individuals will go on to develop AIDS. This is in contrast to many other infections, where an exposed and productively infected individual does not necessarily go on to develop clinically, meaning full disease.

Ebola virus, even; many people can survive that. And I think only, the mortality rate is 40 percent. It just happens to be extremely rapid death.

SS: But in your case, you feel it's more likely that you weren't exposed; or that you resisted exposure?

GC: That I wasn't exposed so much. Because again, then, when I met Pierre — we were together about four and a half, five years — and we were monogamous with each other. Again, partly through choice, partly through drug use being the other lover in our life. And my relatively low libidinal level, I guess. {LAUGHS}

SS: Okay.

GC: Which is kind of ironic and disgusting, because I find the very notion of — well, obviously, abstinence only is anathema to me. I think it's just absurd. I think the Catholic Church is absurd. When I was going to the Amsterdam AIDS conference, in '93, I decided for the hell of it to go to Rome because I'd never been there. And so on the way to Amsterdam, I went to Rome. Had to go to the Vatican. Vatican was filled with riches and gold and just demanded more and more so, an offertory box, reached in my pocket and dropped in a condom.

But my own life, curiously, has been one that's not been characterized by a lot of sexual activity. But I ain't dead yet.

SS: That's right.

GC: I could still be infected. Even with safer-sex practices.

SS: Okay. So I want to get into all of ACT UP. Should we change tape?

JW: Yep.

SS: Okay, great.

GC: Yeah, just saw that two-minute –

JW: That was '92 [Amsterdam Conference]. I was trying to signal you.

GC: Oh. '92, thank you.

Tape II
00:00:00

GC: – and there was a lot of friends from hanging out at Dick's Bar.

JW: Okay, we're ready.

GC: Okay.

SS: Dick's Bar. You admitted to hanging out at Dick's Bar?

GC: I lived on 12th Street. It was my last place in Manhattan before I moved to Brooklyn.

SS: Did you still go there when it was Slugger Ann's?

GC: That, it changed.

SS: Jackie Curtis's grandmother's bar?

GC: Oh my god! Oh, no!

SS: All right. ACT UP.

GC: ACT UP.

SS: So your friend brought you in; your Media Committee friend brought you in, and you saw Garance –

GC: Garance Franke-Ruta.

SS: And that was it.

GC: Yeah.

SS: It was love at first sight. So how did you first plug in to the organization? This is 1989 –

GC: Eighty-nine –

SS: – okay.

GC: – yeah. Well, I started to go to meetings; and pick up the stuff on the back table; and try to understand what everyone was about. And the whole big excitement at that point was the Church action.

SS: This is right before the Church action.

GC: Right before the Chur-, which was December of that year. And I had never been to a demonstration. And like I said, I wasn't really politically astute, for sure. I would say I've always had left-leaning, definitely. I'd call myself a commie fag. In fact, I found somebody's stuff was thrown out in the street, which really looked like somebody – well actually, it was, because I remember reading, there were some diaries there that the landlord had just thrown all this shit out in the street. Somebody died of AIDS. And one of the little buttons that I saved said "Commie Fag." I just loved that one. So I had that on a hat full of buttons that I used to have. Well I still have it, I just don't wear it.

SS: So where did you try to –

GC: The Church action.

SS: Church action, yes. Were you involved with the organizing for that, or did you go to it?

GC: Yeah, I went to it, you bet.

SS: And how did it feel?

GC: Well, I got there a little early. And I came in from the 6 Train, from the East Side. And I was a little, I had forgot which street it was on, kind of, so I came up just north of the church. And I was like, where the hell is everyone? I know it's a little early, but no one's here.

So I, and I saw a side door to the church. And I thought, well, I'll just go in.

So I went in, and I found a pew. And then, it was an earlier mass, and then they stopped; and said, everybody leave the church; got to look for bombs, or whatever.

So people filed out of the church. And then everyone was going back in to see the delightful Cardinal O'Connor.

And as I was standing, as I walked out, it was like, oh, hi, there you are! Thousands of people on the street. It was enormously exhilarating. It was, oh my god, this is incredible! Signs, irreverent; people being arrested. And I just thought, well, okay, I'll stand here on the steps and wait until I go back in.

And weirdly, I was surrounded by these three guys. And they were talking like cops. Because they were talking about the tactics and strategies of the police and the activists and what was going on, who was doing what, on 5th Avenue, etcetera etcetera. But they sounded like they were kind of pro-activists. But they definitely sounded, and so I'm kind of surreptitiously looking at the one guy's lapel, and I, sure enough, I see a little NYPD pin.

It turned out that the fellow that was standing next to me was Sam Ciccone, who was the, one of the founders of GOAL — Gay Officers Action League — of all peculiar and bizarre things. And of all peculiar and bizarre things, he had me over for dinner a couple of times. I don't think it was, it wasn't any interest on my part, sexually, but whether it was on his or not, he never said anything. Which was fine by me.

But I was just, again, I was curious; where was this guy coming from, what was he about?

I'll never forget him telling me, at one point, the role of police officers in New York is to protect real estate. And it was one of the first of a long series of rather shocking comments, that I found shocking at the time, and thought, oh, that's a little bit over the top, don't you think? They bust people who commit rapes and murders and stuff.

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00:05:00

Well, in the intervening years, I have often looked back on that comment and thought, he was so damned right. To the point where I've gotten off jury duty twice by just speaking the truth: When a cop opens his mouth, I think he or she is lying. They do it so, I was arrested a few times. And was – you would ask them the time of day, and they'd lie reflexively. There was no point in saying anything to police officers. So unfortunately, I had this prejudice, which is quite real and quite genuine. And unless I know somebody — and I don't really know any police officers; I knew one in the East Village, that I'd kind of see in Tompkins Square Park. And he seemed like a really cool guy, and straight – sorry; bad word; delete that. He seemed like a good guy, and honest. But that was about the only one.

SS: Did you ever get arrested for drugs? I forgot to ask you that.

GC: Yes. Yes.

SS: So then, when you were considering getting arrested for ACT UP, was that a concern for you?

GC: Yes.

SS: So how did you make that decision?

GC: I basically avoided arrest, for the most part. In part because I wasn't necessarily seeing the point of taking an arrest; but mostly because it just freaked me out. But I did get arrested a couple of times at ACT UP demos. Not intentionally. Not, I mean, I wasn't one of the people that laid down and intentionally took an arrest. I just happened to be the wrong place, the wrong time.

SS: So that never, your previous record was never a factor.

GC: No. As far as that goes, no, it wasn't. The drug arrests that I had – well, I was arrested three times; once for drunk and disorderly at a party in Pittsburgh, and that was fun. It was a bunch of us punks hanging out in the Pittsburgh cells, singing songs, and just had a great night.

Got arrested in San Francisco carrying a knife. The only time I ever carried a knife, and this, I was also carrying a can of beer in a bag. And I thought, I saw people in the Financial District doing it all the time. But you don't do it on Polk Street, when you look like a fag.

And then I got arrested for possession. Which was also kind of galling, because I was with my lover at the time, and we were in a building over on 11th Street. And walking down, out of the building. And as we were coming out of the building — we'd just copped for a friend of ours — and I had the dope in my hand. And so I just put it in my pocket, of this long black coat that I used to wear. And I heard this {SMACK} {CLAP}. That what it sounded like to me. Hole in the pocket as the bag slipped out and fell onto the floor. And of course, the cop said, what are you guys doing' here? And I was say-, Pierre was saying, we're visiting somebody. As I'm saying, we live here! Or vice versa. Already sounding just a teensy bit suspicious.

Of course, we had known, we had friends that we knew, that, we had lived there before. And we had friends that we used to hang out with that copped dope for us a lot. And it was a great family. The daughter was going to school. And she was kind of bright, so I was trying to help her with her homework. And Mama would cook chicken for us while we were waiting for the dope to show up. It was family. And they all knew what was going on. I mean, it wasn't any clandestine thing. It was, we were waiting to cop dope, and hanging out with family.

Anyway, the rookie sees the dope; picks it up. {SNAP} Three days in, going through, jonesing in the system. That was pretty fucking awful. And Pierre had gone through it himself. And that was probably worse, because I didn't know where he was or what was happening, and I was just completely freaked out for him.

So jail and me didn't get along too well. And certainly cops and me didn't get along too well.

SS: Now how did you get into alternative treatments?

GC: That actually evolved because when I began to get involved with ACT UP, I thought, how can I best apply what I know and do that might be useful or helpful?

I was beginning to suspect, in the early, around '90 or '91, that I probably was negative, because Pierre, in the process of detoxing from drugs and getting off drugs, tested negative; and then positive for hepatitis C. So I was pretty sure I had hepatitis C; but maybe I wasn't HIV-positive. But I still hadn't tested, because there was only AZT out there, and maybe ddI coming along; neither of which seemed particularly thrilling or

useful. And I'd watched a few too many friends who did it and died. Didn't really do a lot.

But because I'd had this experience working — and I've always loved science; science has also been a theme throughout my life — I thought, well, Treatment and Data Committee; that sounds interesting. So that's what I got involved with.

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And so I worked with Mark Harrington and Gregg Gonsalves and Kevin Frost and Casper Schmidt. And god, a whole lot of other people. I'm going to have to think about names. Evan Wilder. And, god, who was the facilitator at most of those meetings? He was great. I don't remember. Dark-haired guy? Oh, god. Okay.

SS: Well, what were you working on at T&D?

GC: There were two things I began to do. One, oh, well, if we can have some show and tell.

SS: Show and tell!

GC: Whee!

JW: Ken Jacobson?

GC: Ken Jacobson! Thank you, yes, wow!

SS: Thank you!

GC: God. Names? How old am I? This is one of things that I began to develop, which, and this leads into how did I get into alternative stuff. This was what I called the AIDS Chart, which is a very prosaic, dull name, but what I began to think was what people needed for empowerment was information, and information provided freely. Because one of the things ACT UP did — and I think has had reverberations throughout our society — was really to say, you have to take care of yourself, and you can't rely

solely on your physician. And you have to question your physician. And if you want to survive this damned thing, you better know what's out there.

So what I started out with when I started this was looked at, what are the antiviral drugs; what are the different opportunistic infections; what's out there to treat the different OIs. And at the end of it, then, came alternative stuff and nutrition. Even as a heroin addict, we used to juice back in San Francisco. A crazy — well, very crazy — friend of mine actually found or stole a juicer or something. And he would dumpster-dive for carrots behind grocery stores that threw out stuff that was basically okay. And we'd juice up carrots and apples and celery. And there was this kind of weird health consciousness among a certain subgroup of the junkie scene that I was in. And it made sense. You look at a disease like HIV that causes weight loss and wasting; you might think nutrition might have some impact in that. But it was a rather secondary thing, so the first thing that came up was antivirals. But as this thing evolved, over time — and the other thing about it was, it grew and grew and grew, and we had the ACT UP work space, and I could make thousands of copies of the thing, and just send it out to everybody. Here it is, free information.

SS: What was the title of this document?

GC: I think just AIDS Chart. Yeah, I just called it AIDS Chart –

SS: AIDS Chart.

GC: – and it had different versions. And it was to people living with HIV/AIDS, healthcare providers and their advocates. So just about anyone that gave a shit.

SS: So in other words, there was no comprehensive list of what the symptoms were and what the treatments were, at the time.

GC: No. AmFAR started to do stuff like that as it developed. But I think this was one of the first ones that was out there.

SS: And when is this? Nineteen –

GC: I think the first one was '91. This particular version, 11, is 1994, May 12th.

SS: So you're saying that 10 years into the AIDS crisis, there was no comprehensive list of all the OIs and available treatments.

GC: No, I'm not saying that. I don't know that there wasn't.

SS: Oh, okay. So –

GC: I don't think that there was anything quite like this, because they weren't necessarily also addressing the latest what's in drug trials.

SS: Okay.

GC: There was stuff about cell, immune modulators; cytokine; new antibiotics that were in clinical trials; what we knew about them, what we didn't know about them. I don't honestly remember when AmFAR started to do its book, but I think it was around, probably '92, '93.

SS: So in this era, if you were a person with AIDS, and you wanted to find out what was being developed or tested for your OI, the only place you could get that was at T&D at ACT UP.

GC: It was one of the best places, because we were following all the literature. We were reading *AIDS Weekly*; we were reviewing data; we were discussing

people's experiences with things, or friends that they knew who had gone through; what happened, side effects. And that was something, also; that this reflected some of that. But it pretty much strictly stuck to the literature. But when there was something new coming along, or a problem that was coming up that you weren't hearing about in the mainstream, it would wind up here.

And as it evolved, though, I began to have a kind of switch in my thinking. Now at this point, I probably would switch back, in a certain sense. But at that time,

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there were just a few nucleoside analogues available. Protease inhibitors had not yet come out, although some were in clinical trials by its latest, last versions. And indeed, some of my friends are still alive because they were able to get into clinical trials. Fred Blair was not qualified, by inclusion/exclusion criteria, to enter the indinavir study, but got it anyway, and that's why he's alive. Because I remember seeing him at one point, thinking, oh shit, he's going to be dead in six months. And almost any time I saw that look in people, they were. And he is still here. And doing pretty well. Actually, doing very well. Talk about him later.

SS: So how did T&D, what was T&D's response to your interest in alternative medication?

GC: Oh, there was enough people in there – well, I was, again, I've always been an outsider, and I didn't belong there, either. I'm an outsider because I'm HIV-negative, as I eventually discovered. I suppose '92, '93 I got my first test. I don't really quite recall, but – I realized I was negative. Outsider.

I sat there, and said something like, AZT, as a therapy for HIV, sucks. And the temperature in the room dropped about a hundred degrees, and they really despised me for saying it.

SS: Who despised you?

GC: Oh, I don't want to talk about that.

SS: Okay.

JW: Oh.

GC: I know, I'm going to wimp. No, because I don't want to create that negative energy.

SS: Okay. But you would say overwhelmingly, the position in T&D was –

GC: Pro-drug.

SS: – not comfortable with an anti-AZT point of view?

GC: Yes. The one exception was Casper Schmidt. And Casper and I were involved also in a subgroup of T&D called the Pathogenesis Group. Because that was the other thing that was very fascinating to me; how does HIV cause AIDS? And that was my other – 1993, yeah. Okay, correction: 1992, Amsterdam; dropped a condom off at the Vatican; 1993, Berlin. And I wrote a paper called "AIDS Pathogenesis and Therapeutic Implications." Because to my mind, it was, we don't understand what this disease is doing well enough. But we do have a lot of indications of what's going on. And how can you treat those underlying problems?

Why do CD4 cells die? To this day, we really don't actually know. Most T-cells that die in an infected person aren't infected.

So we had this Pathogenesis subgroup that had Casper, I, Chris DeBlasio, Mark Harrington; who else was, different people sort of came in and out of it. I think Gregg was in it.

SS: Gregg Gonsalves?

GC: Gregg Gonsalves. And Casper was a trip. He was a psychiatrist of Namibian, grew up in Namibia; his parents were Nazis, so he kind of indicated; a white man. And as it turned out, Casper was a bit of a denialist, one of the very early ones, who had this whole concept that AIDS was caused by a disruption in the hypothalamic pituitary adrenal axis, the HPA, which is associated with the increase in cortisol and the decline in something called, a hormone called DHEA, dehydroepiandrosterone. And he took, he would, he would get sulfated DHEA from Italy, and take it. For a long time, I didn't realize that he was positive; I didn't think he was. And he wrote a whole paper on this, and kind of suggesting HIV didn't cause AIDS.

I quickly came to the realization that none of these other explanations – because I looked into this, this whole notion, does HIV cause AIDS? And as a result of this paper, Peter Duesberg, a retrovirologist of some renown, or infamy, called me, and was trying to pick around to see if I thought HIV was perhaps not the cause of AIDS.

Well – Casper Schmidt died of AIDS. And he died of AIDS caused by HIV. Peter Duesberg, it's an interesting split. We don't want to talk about the denialists too much at this point, but it reflects, to my mind, the kind of cognitive dissonance, which is like the clapper in the bell jar of Sylvia Plath, with these denialists. And they will swing from one position to the other with complete ease, as if there's nothing wrong with it. But it's completely – opposite.

SS: Let's go back to your paper. Fourteen years later. So, how right were you?

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00:20:00

GC: Hell, I don't know. I haven't read it for ages. I think there were things that I was – well basically, the paper was kind of looking at the different ways – this still informs the way I talk about HIV. Because the way I looked at it was kind of breaking it down by saying, where does HIV go? You can go to the cellular level; it's CD42 lymphocytes. It can, dendritic cells and macrophages. Then you go to where does it go in the body. It's in the gut, it's in the lymph node, it's in the spleen, the Payers patches. In fact, most of the T-cells hang out in the gut. So we're talking about a disease of the gut.

You can go to a systemic level. How does HIV interact with, and affect, the immune system? Which is more than just saying CD4 cells go down. It's also about – well, the uninfected CD4 cells that die; the disregulation of cytokines, or proteins, that cells release that tell them what to do. You can look at the endocrine system.

So you can look at the immune system; how HIV affects that. You look at the endocrine system, how the hormonal balances can be thrown out of whack. And you can look at the neurological system. And we know quite clearly that, I mean, HIV can cause minor cognitive motor disorder on a, more or less a continuum through various stages of dementia. And that is not caused by HIV infecting neurons. If it does infect neurons, it's at extremely low level, and most of the data suggests that HIV does not infect neurons.

What's it doing? It's infecting astroglial cells that are supportive types of cells in the brain that release these inflammatory cytokines. That damages neurons; that then leads, or can potentially lead, to these minor cognitive motor disorder and dementia.

So this paper was very instructive to me, because understanding these different ways that HIV affects the body point to different types of therapeutic implications. Now the primary one, of course — and the one that's the most successful — is antiretroviral therapy. {CLAP} Whack the virus; you solve a lot of these problems. Unfortunately, the antiretrovirals have their own side effects and toxicities, which are similar, in some ways, to what HIV does.

For example, the nucleoside analogue class of drugs — particularly AZT, or Retrovir; D4T-stavudine, ddI-didanosine or Videx — those drugs impact mitochondrial function. And mitochondria are the little energy producers of every cell, pretty much every cell in the body, and if you don't have those, you die. They're particularly useful in places like the heart, muscles, brain, etcetera – a lot of different places.

So you still have some of these other secondary effects that are happening. Even though the HIV has been pushed down to below detectability, you may still have these other side effects that reflect one of the mechanisms that may be causing CD4 counts to deplete; which is oxidative stress. It's just that it's doing to different cell types than CD4s. Nukes'll be doing it more to, say, peripheral nerves; peripheral neuropathy. Or the pancreas; pancreatitis. Or the muscles, with myopathy.

And again, though, there are all types of interventions that might help to thwart those side effects. Similarly, you have other problems with the non-nucleoside

reverse transcriptase inhibitors and protease inhibitors; they have their own side effect profiles.

SS: So in other words, you were conceptualizing alternative medication as a supplement to, or a way to counteract, the side effects of conventional medication.

GC: No. Not entire-, not only. That's one piece of it. The other way that – other interventions can thwart disease progression. And when I say "other interventions," I want to include drugs that may be off-label, or may be generic; I include botanical interventions — plants, roots, bark, leaves; botanicals have an enormous amount of value — and particularly nutrition. Eating well; stress reduction – extraordinarily important; extraordinarily difficult to manage sometimes. All of these things can have significant impact on outcome. And we're beginning to see some clinical data to support these hypotheses.

For example, there have been two rather large, well controlled, double-blind, placebo-controlled studies — one in Tanzania and one in Thailand — that looked at the impact of a multivitamin; multivitamin-mineral supplement. And in the Tanzanian study, they found the same thing they had seen in a prospective study of gay men in the early '90s that was not controlled. And that was a 30% reduction in the rate of progression of the disease. This is stunning. This is a marvelous intervention. It should be the standard of care anywhere there's a person with HIV.

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Now of course, the first thing you need is good food. And again, this isn't surprising when you realize that HIV is primarily a disease of the gut. And you have all this damage to gut function; villous atrophy and crypt hyperplasia — that is, the little villi

inside the intestines stunt. So you have absorption reduction. You may have OIs in there that can cause damage; candidiasis; CMV colitis; Kaposi's sarcoma. Happily, these aren't as prevalent these days, but certainly they were a significant cause of morbidity and reduction in gut function.

But HIV itself is doing enough damage to the gut. So that it's not surprising, then, that for many years, we've looked at the micronutrient status in the blood and seen these significant declines in just about every vitamin and mineral that a person needs to survive.

SS: Well you make this sound so reasonable. How could people in T&D have trouble with this? What was the issue?

GC: Well, it's more reasonable now because we have more data now. Back then, there were no data. And the focus and interest at T&D was primarily drugs. And also, a lot of their work was focused on working with — sometimes a little too cozily — the drug companies, both in terms of the development of new drugs as well as in the pricing of drugs. So, I mean, it was more, I don't think that there was necessarily an overt hostility. On some part, among some people, there was. Because it was simply dismissed as – I think they kind of assu-, if I want to psychologize it a bit, maybe it wasn't macho enough. A drug, by god, that's really doing something! But this shit isn't really going to keep you alive. I want something to keep me alive! Don't talk to me about fucking vitamins and herbs. I want a goddamned drug to live!

And somehow the notion that a vitamin could do that was a little bit ludicrous. We didn't have the kind of data that would have supported the notion. And to this day, now we have this asshole Matthias Roth from Germany, hanging out in — I

think he's a German — hanging out in South Africa; going around telling everybody, all you need is a multivitamin; you may now discard your antiretrovirals.

SS: Well, what about the other tendency in ACT UP, which was the more radical alternative people? I'm thinking of Jon Greenberg and –

GC: Right.

SS: What was your discourse with them?

GC: Ah. Oh, you know, I didn't, I did go to some alternative and holistic meetings. When I began to realize what they were doing, Jon Greenberg was a hero of mine. Because he was saying exactly what I was thinking too, which was; some of this stuff looks damned interesting. It seems to be keeping some people alive a lot longer, which it did; and why don't we do clinical trials and figure out if this stuff works?

I remember going to, I think it was, there's a series of conferences called the Keystone Symposia, which are very high-falutin' scientific conferences – not particularly necessarily AIDS, but they did have a, they do have a Keystone AIDS conference. I managed to go to one of them in Albuquerque — '93 or '94, I don't know — and I remember getting up. And Tony Fauci, the director still, after all these decades, of the National Institute of Allergic and Infectious Diseases of the National Institutes of Health, had given a lovely presentation. I think his presentation was on superantigens. Which turned out to be not the case. Although, and it was kind of obvious at the time it wasn't likely to be. The beta subsets were not perturbed in a way that made it look like a superantigen. There's a little bit of magical incantatorial science stuff I'm not going to explain.

Anyway, I get up to the microphone and say: Dr. Fauci. There are people out there who are using a number of different interventions with a significant dearth of data. And I'm wondering when is the NIH going to begin to do clinical studies of things like bitter melon and curcumen and glycyrrhiza. And I could feel the temperature in the room plummeting as these scientists were hearing this litany of – plants. And micr-, and vitamins.

There's this whole – it's a twofold thing. One, there's this cultural identification with those types of interventions as being flaky. And ineffectual. And certainly not as good as a drug.

Tape II
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Then of course there's the whole, simply the monetary issue. You can't patent herbs and vitamins and things like that, so you can't make billions of dollars on it, so who the fuck cares?

SS: Can you say that again?

GC: So who the fuck cares?

SS: No, start at the beginning. You can't patent –

GC: Uh, {LAUGHS}. You cannot put a patent, and make billions of dollars, on a botanical or a vitamin. And that brings me to my other show and tell piece.

SS: Okay.

GC: Wonderful book! Read it!

SS: Is that a new book?

GC: Relatively.

SS: I just want to ask you. I want to stay with what we're talking about, before we get into this new book.

GC: Okay. Two thousand four.

SS: Here's the problem: the people who I remember — like Jon Greenberg — standing up at an ACT UP meeting and saying, what about garlic? Those people are dead. And the people who are still alive are – that's not true. Okay.

GC: Nah. Come on. Chris DeBlasio's dead; Carleton Hogan's dead; Evan Ruderman's dead. A lot of people are dead.

SS: Because it feels like a lot of the T&D guys have done quite well, over the long haul.

GC: Some of them have, and some of them are very fortunate. I think Mark Harrington did well because he didn't start treatment till much later. The people that I know that took, I know lots of people that took AZT who are dead. From the Wonder Bar; Jeffrey and Tim. They used to do, Monday nights, when I was playing hooky from ACT UP; I'd go to the Wonder Bar. And Jeff and Tim had movie night. And Jeffrey knew everything about the movies! He knew all the inside stories about the actors and who was screwing who and just fun stories, too. I mean not just gossip.

AZT for five years. Dead.

SS: So you're saying the difference – that all the other things aside –

GC: Aldyn McKean dead; Rob –

SS: I want to ask you about Aldyn in a second, but – so you're saying that starting treatment too early is a significant factor in terms of who lives and who dies.

GC: No.

SS: No.

GC: No. What I mean is that people who started, when AZT came out, in '87, first of all, they killed people with the dose; 1200 milligrams a day was too much. Quickly dropped to 600. There was a study done by – I forget her name. They looked at, actually, 300 milligrams of AZT a day, and that worked just as well. A lot less toxic. But, as monotherapy, it sucked.

There are a few people I know who are still alive. But what happened was a lot of people, they started on AZT. Then they maybe went to ddI. Then they went to 3TC or ddC. And maybe along the line, they came up with AZT-3TC. That did a little bit better. But they kind of went through this sequential series of monotherapies, to which they developed resistance. And then by the time the protease inhibitors came around, if they lived to see that — which too many didn't — then they had opportunities and options. But a lot of them were kind of hurt by the fact that they'd been through these sequential monotherapies and developed resistance.

As to now, currently; when is the best time to start; I think that whole issue and debate is still open. I think, clearly, if you're below 200, start, period. If you're between 200 and 350, the thing to look at is, to my mind, the rate of CD4 decline. In other words, how fast are your T-cells going down? Are they kind of like sticking' around at 260? There may be other things you can do to delay progression and delay the need to start antiretrovirals. Okay? And maybe you don't need to. But if you've, you know, you've got 260 and then your next test is 220 and the next test, it's two-five; start.

SS: Okay, I understand. You're talking about early on –

GC: In the evolution of –

SS: But historically, looking back on ACT UP — and I'm thinking of our friend Jim Lyons, who died a couple days ago; and when we interviewed him, he talked about this issue. That people who historically started medicating too early in the process of drug development are the ones who had the hardest time living.

GC: Right.

SS: Within our community, the ACT UP community.

GC: Yeah.

SS: So you would say that that is so.

GC: Yeah, I think it is, largely. Most of the people I know from that time are dead. And again, I think it's partly because some of the other folks started at least with dual combination therapy. And that might have given them a better bang for the buck.

Tape II
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By contrast, you can't say that alternatives – I mean, my friend Michael Onstott is dead. But he did antiretrovirals. And he also did a lot of alternatives. The problem is there's no cure for AIDS. The problem is the drugs we've got still suck. Steve Kovacev is still alive. And that guy has had, he had three T-cells for a helluva long time. He did all the alternative stuff. He was a bit of a denialist for a while. In the late '80s, early '90s, kind of realized that none of the crazy excuses denialists come up for as to why your T-cell count is going away and you're getting PCP and cryptococcal meningitis, you know, you did drugs? If you did, if drugs caused AIDS, like that asshole Duesberg says, I'd be dead! I'd have a helluva lot of straight friends that are dead, from AIDS!

SS: Can you spell Mike's and Steve's last names?

GC: O-N-S-T-O-T-T; Michael Onstott, from San Francisco. Great guy, he was a sweetheart. And Kovacev is K-O-V-A-C-E-V.

SS: Okay.

GC: He's up in Boston.

SS: Let's talk about Aldyn McKean.

GC: Okay.

SS: How did you meet Aldyn?

GC: Oh god, when did I meet Aldyn? ACT UP. Can I remember the first time I met him? I'm sure it was just seeing him on the floor. I fell in love with him, in a way, not, not in a sexual way, not in a, although he's hot, I mean he was definitely a hot guy; wouldn't-a kicked him out of bed. But I loved him so much. Just his compassion, his energy, his – his brilliance, his insightfulness. Yeah, and his compassion; he was such a compassionate, good-hearted man.

SS: Is there a particular story or event about him that you –

GC: Oh, just like running into him at a bar. I forget which bar — it might have been Tunnel, or it might have been Dick's — and he was with a friend. And he just started singing songs. And carrying on. I think one of the most heartrending scenes was when he came to me and asked me what I thought – he told me he had this kidney disease. And sadly, I can't remember the name of it. But I remember, at the time, just kind of giving him this stunned look, like, aw, shit. Because it was almost always fatal. And – I was, I'm an activist, I'm not a doctor. And I didn't know enough about alternatives, or things that he could do to help prevent the kidneys from collapsing. And I

think he saw that look on my face, and he knew what it meant. But I think, I, I hope he merely interpreted it as, I don't know; but it ain't good. But, that I'm just ignorant.

SS: But didn't that happen a lot, like when you became a science expert inside ACT UP, that people would be constantly asking you personal questions about their own treatment?

GC: Yeah, sure.

SS: And what was that kind of responsibility like?

GC: It's still going on today. First of all, I try to make it clear that I'm just, I'm offering suggestions based on what I've seen of data. I try to, if people want data, I give them the data. Somebody says, I've got neuropathy. This is not something that I get too. I freak out to the extent that, god, that is a horrible thing to suffer. And it can be mild, so it's not that bad. It can be crippling. There are some interventions that might help. Maybe, we know, for example, acetylcarnitine; three grams a day; they did a study in England. And it seems to help attenuate the disease. So that's an easy one.

When I brought my brother up from Albany to go to my father's funeral a couple of years ago – he was drinking really heavily; he was a biker. And covered with tattoos. And I went to the room that I put him up in – like I got the money to do that, but he didn't. And he was getting really drunk. And he said, I gotta drink for the pain. I've got all this fuckin' pain. Because I have cancer. And he started crying, because he said, I don't think I'm going to make it.

And I said, no, I don't think you are, either. And I had to do that with my brother. Because I also knew him. I knew he wouldn't really, I knew it was metastasized. But what I did do is I said, look; go to the hospital. They'll get you set up

with drugs. They'll get you hooked up with Medicaid. Just go to the hospital; do the drugs. It's better than fucking drinking. It works better. Get morphine.

And he did. And he cleaned up, he dried out, and he started painting again. So the last four or five months of his life, he drew, did some of these beautiful paintings, that were his quintessential style. I love my, the way he did this stuff.

Tape II
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My brother and I had a kind of a hard relationship. Because he was, he was a biker, and I'm not exactly that type. And so sometimes people look at us, say, my god, how did you two come out of the same womb? And then other people that kind of know us go, oh. Uh huh. I s-, yeah. And he died in May.

SS: Okay.

GC: So, to my mind, it's, I just offer what I know, that people can try. And I try to offer people ideas of how to test whether it's working for them. Because you know, at the end of the day, whether we have data on something or not, or if it's more limited to very sparse data, or even anecdotal data, and people want to try something; I say, well, there's different ways you can try to experiment. Even if you have a drug that has a wonderful data set, that says, this drug works; when it, at the end of the day, you have to take that drug and you may or may not have side effects; you may or may not have benefit from it; and only you are going to figure out the statistics don't matter, except to the extent that they give you a little bit more encouragement as to whether or not this might have a benefit for you.

So what do you tell a person that wants to try something for which there are fewer data? Same thing. You want to try some liver herbs to see if it'll clear your liver out. Well, try to stabilize whatever you're on for a month; go do blood work; start

the stuff. Do blood work a few months later. Does it help? You have fatigue or diarrhea. Try it, see if it helps.

SS: Okay. I think we just ran out of time. We're going to change tapes.

GC: Good. I'll have a smoke.

SS: You want to take a bathroom break, or something like that?

GC: Yay, pee!

SS: Okay, so here's a question: What would you say are the effects of the cocktail?

Tape III
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GC: Well, if it's an effective cocktail, it'll drive viral load down to below the limit of the tests that can detect the virus, their ability to detect it. So it will then result in a lot of immune reconstitution, which unfortunately can cause immune reconstitution syndrome, which for some people can mean a reflare of OIs, opportunistic infections like MAI. So that could be a problem. Tuberculosis can be a problem. It can make people have tuberculosis response, because the immune system is starting to work again.

But for the most part, it will help the CD4 count, generally, to go up.

Now, what does that mean? Are these new T-cells that are being produced by the thymus, which is where T-cells kind of, the gland in the chest that T-cells go to – are being created? Is it redistribution of T-cells that have been sequestered in lymph tissue, and now coming back into the blood? A little of both. And it helps, though, because there's not so much inflammation in the gut, we actually also see some reconstitution of micronutrient status, for example.

But then again, as I saying before, a cocktail will also have some side effects, depending on what the constituents of the cocktail are. Almost always, it's going to be, have a nucleoside analogue backbone. Which means that it'll be these drugs that cause that kind of damage; to mitochondria, to fat cells, muscle cells; things like that.

Protease inhibitors will have other effects, maybe on body distribution. Non-nucleoside reverse transcriptase inhibitors can have effects, like efavirenz or Sustiva, will increase cholesterol; as well as protease inhibitors can increase cholesterol and triglyceride levels.

So you have a whole series of side effects that can arise from the use of a cocktail. Some people have no trouble with it at all. Other people can have very serious trouble; pancreatitis, peripheral neuropathy, heart problems, lung problems. So it's a mixed blessing.

The other horrific side effect of antiretroviral medicines is the impact on economies. And you can look, for example, on the global stage, where most people on the planet still don't have access to antiretrovirals; driven largely by the pharmaceutical industry, that very often had very little to do with the research and development of these drugs, many of these drugs. We actually paid for it, from the government, which I think is fine. But then the government just handed over the licenses, and they turned around and screwed people to death. And they're screwing people to death all around the world.

The Bush, President Bush — I say that reluctantly, because I don't believe he really is the president; I think they stole both elections; I think there are ample data to support that contention, as well; although it's arguable — created the PEPFAR program with a certain number of countries in Africa and a couple in this hemisphere; and that

program was designed, in part, to get antiretrovirals. But it also suddenly placed the Food and Drug Administration as the arbiter of which drugs should be used for the globe. Now the World Health Organization already had a program like that, to establish the equivalents of generic drugs. And that, of course, was sidestepped because Bush has a complete disdain for the United Nations, as reflected in having had that John Bolton bastard in there. And as an interesting result, all these PEPFAR countries; even though the FDA has actually done a fairly decent job in approving a variety of generic drugs, has failed to actually implement the use of any of them. So the costs of these drugs are outrageous. They have destroyed AIDS drug assistance programs in this country, which are each individually run state by state, to the point where now we have waiting lists of people who are waiting to get drugs because they have to spend so much to feed the gaping, horrific maw of the pharmaceutical industry. And pharmaceutical industry has continued to lie and cheat and steal and murder — acch! — and just for James, there behind the camera, I'm going to say the word — commit what I call an economic form of genocide.

Tape III
00:05:00

It doesn't necessarily fit within the parameters or the definition under the Geneva Conventions that defined genocide. However, I think it's an apt term. I actually got the head of Glaxo Smith Kline to say the word at a conference that he had the audacity to join with Médecins Sans Frontières – Doctors Without Borders. And I essentially said this to him. And he said, well, I don't think it's genocide. I said, well, it's in your mouth.

SS: Do you feel there is complicity historically, looking back, between ACT UP and the pharmaceuticals? And if so, can you give me an example?

GC: Complicity. I think there was a lot, and there is still a lot, of well-meaning intent. But there is a phrase — and I forget who came up with it — called colonization of the mind. And I think that many people who felt that they were cozying up with and working with or meeting with pharmaceutical company representatives began to buy their bullshit; and not realize the extent and degree to which they were buying their bullshit.

SS: Can you give an example of a particular pharmaceutical?

GC: Mm, that's a good question. Because I was so loath to be involved with those, I have gone to pharmaceutical company meetings, where I've said exactly that, actually, to a roomful of activists. Let me think if I can remember which company, it was probably Hoffman-La Roche.

What always tended to bother me was that they tried to be so reasonable with them, in terms of saying what price a drug should go out at.

SS: ACT UP, you're saying.

GC: ACT UP. Or, ACT UP, Project Inform, whoever was involved in these things. It would be more TAG at that point, because TAG — Treatment Action Group — split off from ACT UP; but they were many of the people who were originally involved in the Treatment Data, T&D Committee, of ACT UP.

And it just always seemed to me peculiar that they would do this kind of thing and think that it was somehow okay to be reasonable with these fuckers. Because they're, they're not reasonable. There's another good book, called *The Whistle Blower,* which I'm starting to read. And it's kind of a disgusting account of a guy who was with, was it Pharmacia Upjohn that was then bought by Pfizer, which is a really vile,

despicable company; makers of the drug fluconazole, or Diflucan, which they made sure a lot of people died unnecessarily of cryptococcal meningitis in Africa because they couldn't access the generic form, from Thailand. Seventy cents versus 12 dollars a day, for example, in South Africa.

Pfizer bought Pharmacia — I think it's Pharmacia — and as this guy who worked for that company pointed out, they did the same thing they did when they bought other companies; they basically screwed everyone that worked there, and got rid of them. Put their own people in. And basically, it's all about generating income.

SS: Okay, but focus on ACT UP.

GC: Yes.

SS: Because you're giving me a very general criticism. And I want to know if there's really a specific moment, or specific example, where you feel that ACT UP did not fulfill its responsibility vis a vis a particular pharmaceutical company around a particular issue or drug.

GC: I'd have to think about it.

SS: Okay.

GC: The one area that broke my heart was what we called the McClintock Project. And that become the AIDS Cure Project. And that was intended to be a sort of Manhattan Project on pathogenesis. Pathogenesis is the word used to describe the way HIV causes AIDS; how does it disregulate immune system, etcetera. And we received, from some very stiff opposition, particularly from Project Inform; also from some people within ACT UP; that this was not a good source of, a good way to utilize resources. And I found their arguments somewhat despicable.

Tape III
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Another example was the CRADA [Cooperative Research and Development Agreement] agreements.

SS: No, wait. Go back to the McClintock; I need you to be really specific.

GC: I know, and I'm horrible at this, because I don't remember.

SS: But I need you to tell me, like what the McClintock Project was going to do that this faction of ACT UP objected to, for what reason.

GC: You see, the terrible thing is, I don't remember their rationale, except that, beyond the point that they felt it was not a reasonable use of resources? And I can't re-

SS: Now why do you think they were wrong?

GC: Because I think we'd know a lot more about how this disease operates – because I think that they bought the notion that the only way we were going to find treatments for HIV was to follow the capitalist model, because that's what existed. And anything more radical than that, that was a threat to that, would stymie further research and development of drugs.

SS: But what specifically would the McClintock Project have done?

GC: The McClintock Project was not about drug development. It was about understanding how HIV causes AIDS, and from that, understanding better targets for antiviral –

SS: But how were they going to do that?

GC: By collecting a group of scientists from disparate fields into a center or a site where their entire focus and effort would be — and well funded — would be to

determine how HIV causes AIDS; and with that deeper understanding, understand better ways to treat the drug, from not only antiretroviral perspective, but from a vaccine perspective.

SS: So are you saying that there was no high-level think tank around AIDS that was not linked to a pharmaceutical company?

GC: No, I'm not saying that. I think that the National Institutes of Health and a lot of European researchers – in fact, I'd say the more interesting work in pathogenesis very often was coming from researchers in Italy, France, Germany to a certain extent.

SS: So what would McClintock have done that these people weren't already doing?

GC: It would have brought these disparate communities together. It would have brought them under one umbrella, where their entire focus was AIDS. Whether you're bringing in endocrinologists and immunologists of, different types of immunologists.

SS: So you are saying that that kind of thing did not exist.

GC: No, that didn't, no. That particular type of project did not exist. But not necessarily that it wasn't linked to pharmaceutical interests. Do you see what I'm saying?

SS: No.

GC: To the extent that pathogenesis work was being done, I think it was mostly being done at NIH. Drug companies don't do that; they don't care. What drug companies do — if they do anything at all, and not just wait until some small company

comes up with an idea that they then purchase; or the NIH comes up with a drug — to the extent they do anything, what they do is drug development. And what they'll do is they'll look at the protease enzyme, and then get a 3D crystal structure, maybe, and then try to figure out how to fit a drug into the pocket of the protease. But that's what they're interested in; they're interested only in the antiviral approach.

SS: Right, I understand that. But –

GC: Which is what you would expect.

SS: – so you're saying that NIH was doing what McClintock wanted to do.

GC: In a very haphazard, unfocused way. They did, they did that kind of work in understanding pathogenesis. If you were to find, to the extent you were finding it happening anywhere, it would be NIH.

SS: Okay –

GC: That's all.

SS: – I don't totally understand, but that's okay. Okay.

GC: That's also partly because it's been so long since the McClintock Project, which became the AIDS Cure Project, happened.

SS: Well then let me ask you an even harder question.

GC: All right. That I may not have a good answer for.

SS: The global crisis in access that exists today; can you trace that to these early activist relationships with pharmaceutical companies? Is there something that could have been built in, in those early days, that could have avoided what we have now?

GC: The very first ACT UP action, which I didn't go to — it was before my time — was Wall Street. And the reason that people were there was because of the price of AZT. And it was coming out at 10 thousand dollars. And they did have some initial success in getting it marked down a little bit. But as I recall, at the time, too, Burroughs Wellcome, which later become Glaxo Smith Kline, simply raised the price of acyclovir, which is another extremely important drug for many, many people with HIV. And in fact, may be useful in Africa. Well, that's another story.

Tape III
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At that point, as drugs began to be developed — and it became clear that the combinations were running anywhere from 12 to 20 thousand dollars per patient per year — the perspective, I think, most of us had — myself included, I'm sorry to say — was that that's, this is the way things are; and there's nothing that we can really effectively do about it, unfortunately; and so those people are going to die. And what the hell can we do about it?

So I think that there was a buy in, too much, to this idea that they had all the power; we have none; and there's nothing we can do. And it wasn't until '98 or '99, when Cipla came around, and said, hey, we can make this shit cheap; and suddenly, hope began to bloom.

SS: Was there any voice inside ACT UP that critiqued this at the time?

GC: At the time? You mean, like in the '90s?

SS: Um hm.

GC: I don't recall particularly. I mean, I'm, the only thing I can think of internationally that we did was when the Haitians were being held at Guantanamo, and different places. Hm, history repeats itself.

SS: Is it the exact same holding facility?

JW: Yeah.

GC: Yeah. Yeah. Grisly, huh? And, hah, I'll never forget Bob Rafsky being at the back table, and going what the fuck are they talking about this for? This ain't going to save my life!

I said, Bob, come on. Their lives matter, too!

But was there any kind of global – we weren't global then. Everyone was just so desperate, trying to stay alive or help their friends stay alive, for so long, that there wasn't really an opportunity. Eric Sawyer knows this stuff a lot better than I do.

SS: So could you trace the current global access crisis to a lack of vision in ACT UP at those crucial moments?

GC: I don't know – yeah, in a certain extent, it's a lack of vision. I think there was a lack of – really – figuring out more novel ways to attack the industry. I think that's because there was this fear. Because the industry was, was and is holding all our lives, mine included – as a person living with hepatitis C — hostage. We're being held hostage by them, because they say, if you fuck with us too much, we'll stop looking at your drugs, we'll stop developing them. And then where will you be?

And so there was this kind of Stockholm Syndrome happening; that if you, if you argue too much, or yell too loud, and you aren't reasonable with them, they'll screw us horribly. And when you have – the real complicity happens with the NIH and

the FDA and the Health and Human Services. And that's when I get back to the CRADA agreements. And the CRADA agreements arose, I think, out of Bayh-Dole, which was ostensibly to kind of put a cap on it. So that, in other words, if a lot of the research on a drug had been done at the NIH, at taxpayer expense, including early clinical trials; and then that drug was licensed to a company, to complete the development piece of it; that they would simply agree not to screw the crap out of people. I'm sure that's not exactly the terminology they used in the CRADA agreements, but essentially that's what they were.

And one of the things I'll never forgive Peter Staley for — as I understand it, and forgive me if I'm wrong, Peter — but was that he went down to Congress, and testified, as an activist, that the CRADA agreements were stymieing AIDS drug development. And I think that was a horrific mistake. I think that was the kind of thinking that characterized a lot of treatment activists.

And to this day, I'm very disappointed with the AIDS Treatment Action Coalition, this ATAC group; which seems to hand out a lot of money to people of color to learn how to be – so-called pharmaceutical – pharmaceutical-company aware, so they can go to these meetings and do what? And it begins to almost smell like one of these grassroots organizations that, Schering-Plough, for example, was famous for, around hepatitis C; creating grassroots organization fronts that were really nothing more than marketing tools for them. Which, actually, in that book I mentioned, Marcia Angell mentions.

Tape III
00:20:00

So that kind of colonization of the mind, I think, had a really enormously deleterious impact. Yet, on the other hand, I didn't come up with any particularly good

strategies or ideas to say, how do we deal with these motherfuckers? I still don't know. I wish I did. The only thing I can think of is not something I care to put in print.

SS: Okay. Let me just ask my colleagues here. Do you guys have anything you want to ask on this subject?

JW: Do you remember, I think the controversy against the AIDS Cure Project was they wanted development of OAR.

SS: What's OAR?

GC: Office of AIDS Research.

JW: Office of AIDS Research.

GC: Yeah.

JW: When's the last time you heard that? So they wanted to make that basic research as a government component.

SS: Oh, that was what the McClintock Project wanted, or the, yeah.

JW: Yeah, well, McClintock was going to be an independent – You can maybe take it from there.

GC: Yeah, that, thank you, that's a good reminder. I mean – again, this is – in fairness, I think what they were, wanted to do with the Office of AIDS Research was create something practical; where they felt that the McClintock Project was not politically practical and wouldn't get the kind of funding that we were seeking. Although these were the Clinton years, and the AIDS Cure Project, I think, could have been something that we got money from Congress. But they felt that this was a competition to the Office of AIDS Research. And its design was to address the overlaps and gaps in the different institutes.

The National Institutes of Health is composed of these different institutes, centers and divisions that address different aspects, from kidney and heart and infectious disease. And different agencies within the NIH were doing different kinds of research. Some of it was this was doing one thing, that was quite similar to what they're doing over here; and so there's an overlap. Why not have this Office of AIDS Research coordinate these activities so that there was cooperation and working between them? And then also, as gaps became apparent, where there wasn't research being conducted, those gaps could be filled.

Early on, actually, I got a group together to go down to visit with William Paul, who was one of the first directors of the OAR, to address specifically, again, complementary and alternative treatments for HIV. I think at that point the Office of Alternative Medicine had existed, but it was very poorly funded. Now, it's the National Center for Complementary and Alternative Medicine. I think it has a couple hundred million; I don't remember the exact budget, but it's more substantial than in those days.

People that joined me there were Carlton Hogan, who was a marvelous fellow, who worked at the CPCRA in, Minnesota? Great guy; great activist. He died a couple of years ago. Kiyoshi Kuromiya; Lark Lands. Kiyoshi was ACT UP/Philadelphia; amazing, amazing man; loved him. I think Michael Onstott was there. And we presented different ideas, both in terms of what was the evidence that suggested some of these interventions might be of some benefit; and what were the types of methodologies that we might use to address how to evaluate whether they're useful. Of course, double-blind placebo-controlled. But Carleton had this marvelous idea called MAPS, or Multiple Antiretroviral Protocol Strategy. And this was to look at clinical

endpoints. Now, with most of AIDS research, we look at surrogate markers. That is, what happens to his T-cell count; what happens to the viral load. And this was a kind of a way to capture a lot of information about complex things and see how a clinical outcome came. Did people die; did people get sick. So morbidity and mortality, as opposed. These are actually better ways to do research, but they can also be more expensive and may involve more people.

Paul, didn't get any of it. Nice guy; immunologist; discovered interleukin-6; marvelous; should have stayed in the goddamned lab. But again, this was one of these conflicts that arose. And they felt that the best way to practically address research needs was through this development of the OAR. And they're, the OAR still exists. I'm not quite sure what they do, but I honestly don't follow the work. And I know they, and I, to that extent, I supported the idea of an OAR; I wasn't against it. I don't think that they were necessarily mutually exclusive ideas. But I think they got it in their head, there's this little limited pot, and we shouldn't push for too much. Like we shouldn't push the pharmaceutical companies too much. They won't give it to us anyway, so if we can at least declare a little victory, that they didn't screw us that bad; well, gee, we did something!

Tape III
00:25:00

SS: And who were the people in ACT UP who supported OAR, and who were the people who opposed it?

GC: I don't know who opposed it. Supported it; Mark Harrington was the big spearhead, and Gregg Gonsalves. They were the two guys that really did a lot of work around it. And Mark always did amazingly good wonk work, in terms of really analyzing, in a very meticulous and detailed fashion, what was spent; how it was spent;

where it went; what was wrong; and he has that kind of a mind. And I admire him immensely for that. And I think a lot of that work was important work, because nobody else was doing it. So it took someone from ACT UP.

Were there people opposed to OAR? There probably were. I honestly don't remember.

SS: Okay.

GC: Yeah. Sorry.

SS: I want to move on to my final category.

GC: Okay.

SS: Jeopardy.

GC: {LAUGHS} What is life?

SS: It is –

X: Every answer is worth twice –

SS: As an ex-addict, in ACT UP, what was your relationship to needle exchange?

GC: Ooh. Huh-huh-huh. I love Richard Elovich; he was a kick; is a kick.

SS: Another ex-addict.

GC: Another ex-addict. Totally, utterly, completely, a hundred percent supported it; couldn't do it. Wasn't ready. I wanted to. I really wanted to get involved with needle access; and work with people. But I, even though I knew I was pretty much over it — and I had that experience where I walked by; could have done it; didn't — I didn't want to just put myself in the situation of constant-, so I was a bit of a chickenshit. Sorry to say.

SS: Do you think that needle exchange would ever have happened if there had not been recovered addicts in ACT UP?

GC: Nope. Not in a million years.

SS: Why is that?

GC: Because we live in a devoutly, profoundly racist and delusional culture, that thinks this war on some drugs is somehow beneficial. And yes, it really is; to the multimillion-dollar prison industry. It has absolutely no benefit whatsoever for anyone who is addicted to anything, whether it's heroin, crack, Xanax, alcohol, tobacco. It doesn't do shit. It spends an enormous amount of money and resources, and it's, of course, puts a lot of black people in jail, a lot of Latinos. It's enormously racist, as this country always has been.

There, a great study, just to go off on a slight tangent. They did evaluations of health outcomes and healthcare access along income levels. And kind of had this feeling that maybe, you know, health access is more, first on economic lines. You're poor, you're screwed. Like me; I have no health insurance.

But the study showed that African Americans, versus Caucasians; as you go up the income scale and look at their health outcomes, even at the over-$50,000 mark, African American health outcomes are worse than their Caucasian counterparts. Underscoring the profound racism.

They didn't come to any particular conclusions as to why this is. But it could be location, where you are. But maybe it's just that you show up at a hospital, and the physician just has subtle, or overt, racist tendencies.

SS: Yeah, but stay focused on ACT UP.

GC: I know.

SS: I mean –

GC: Sorry. But this is ACT UP. That was the great thing about the 20th anniversary action, was so many people of color. And I swear to god, that's why we didn't get, one of the reasons we didn't get much coverage.

SS: But there were quite a few recovering addicts in ACT UP.

GC: Um hm.

SS: And –

GC: Or current users, too.

SS: Well, that's my next question.

GC: Yeah.

SS: What was your sense of how much needle use was actually ongoing in ACT UP?

GC: Needle use; probably not all that much.

SS: Let me rephrase that. Let's talk about Rod Sorge. That's actually where I'm going with this.

GC: Okay. Oh, okay.

SS: Because he died of a heroin overdose, right? And he was involved in needle exchange –

GC: Right.

SS: – as an open user.

GC: Right.

SS: And some of the other organizers of needle exchange were definitely not using anymore.

GC: Right.

SS: So what was the discourse between those two groups — people who wanted to continue to use, and people who were completely not using — as needle exchange was being built?

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GC: I didn't know, because like I say, I chickened out, and I didn't get involved. And I knew Rod; I didn't know him that well. I could speak more to, the Thai Treatment Drug Users Network –

SS: Okay.

GC: – and knowing what they're up to, and –

SS: In relation to ACT UP.

GC: In relationship to ACT UP, that will be when James goes over there and starts to introduce them to ACT UP, and creates ACT UP.

SS: Okay, well let me ask you; when you were in ACT UP, were you aware of drug use inside ACT UP?

GC: Yeah.

SS: And what –

GC: Not extensively.

SS: – not extensively.

GC: No. I mean, I, I didn't – see, again, I'm an outsider.

SS: Okay. But was there acknowledgment of other – between people who were former users, was there acknowledgment?

GC: Acknowledgment of the use? Or that people were currently using?

SS: In other words, was there a closet for ex–drug users in ACT UP, or was it part of the discourse that helped us develop policy?

GC: I don't think there was a closet. Because as far as I remember, anybody that was involved with it was quite open about what they were doing. Maybe some people were not necessarily – admitting to using. But I don't know. Because that never – that's one of those personal-choice issues; it's a person's own business. And it's their own business whether they choose to discuss current use. So I just basically was there to support people regardless.

SS: Okay, let me say it differently. Because I think last time I asked you the questions, would there have been a needle exchange –

GC: Oh yeah.

SS: – without the presence of ex-users and you said, absolutely not. But then you went into a very theoretical, abstracted conversation, that did not –

GC: I never do that.

SS: If I could ask you that again, and you could give me a specific answer that has to do with ACT UP. So it's like, what was the role –

GC: Oh.

SS: – of ex-users in ACT UP in creating needle exchange?

GC: It was because people recognized – those of us who'd used needles knew that this was a good way to get infected; and a way that a lot of people were getting infected. And with the law against having access to syringes in New York, etcetera, made it real difficult.

I remember works. So, concealed works.

SS: But how was that expressed in ACT UP? Did people stand up, and say, I am an ex-addict, and I know that we have to have a needle exchange program, based on my own experience?

GC: Do I recall, I'm sure Richard must have said that at some point? I remember – I, I heard him say it in PS 122, I think.

SS: Oh well. I guess you can't give me what I'm looking for.

GC: I'm sorry. As far as I recall, yeah.

SS: You're saying that the presence of ex-addicts definitely had an impact on creating needle exchange, but you're not telling me how.

GC: Because we were the ones that knew that it was an important thing to do.

SS: But did you say so?

GC: Did I –

SS: On the floor? In other words, how was the group persuaded that this was important? Because it was a priority issue for ACT UP.

GC: Yeah, it was.

SS: And how did it become that?

GC: Because, I, as far as, I just ass-, I, I – I can't remember a specific time that somebody actually got up and said, I'm a drug user. But I'm sure it happened. It must have. I did. I never denied it.

SS: Right. But you don't remember a specific dialog or discourse about this.

GC: Sorry, holes in the brain –

SS: Okay, that's fine.

GC: – from all my drug use.

SS: That's fine, that's fine.

GC: {LAUGHS}

SS: Let's see. Do you feel that there was a time when you left ACT UP? Or do you still consider yourself to be a part of it?

GC: In spirit, I feel like I am still a part of ACT UP. And I'm, of course, with the 20th anniversary activity, I became involved a bit. But in, I stopped going to meetings regularly.

SS: When was that?

GC: Probably about '96 or '97, I guess?

SS: And why do think that was?

GC: Well, the meetings were getting smaller and smaller and smaller. And there would, it would, at first, there were hundreds of people; sometimes a thousand people would come to Monday night meetings. And there was all that energy and focus. And then, unfortunately, there became, it, the protease inhibitors came along. Marvelous. People started to live; people weren't dying so much. You didn't hear about KS; you didn't see people with KS lesions –

SS: Um hm.

GC: – as much. You didn't see people dying quite so often. And yet, how many have we lost in the last 10 years, 11 years? So many. But we didn't have the power or the strength in ACT UP/New York to go out and put together a huge

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demonstration. This 20th anniversary action, um – so many people died, too, in the early years, that were the, the movers and shakers and that did things and got things, got actions going; came up with chants, brilliant chants. Still a lot left, thank heavens. Oops. Well, thank something; I'm a devout agnostic, so – I retract that.

And that's the thing, also, that scares me the most. Because I don't know how we're going to have the power to effect the changes that we so desperately need. We need single-payer health care. ADAP was a nice Band-Aid. But there's no HEPDAP; there's no DIABDAP, or CANDAP, for cancer. So we're, if, I'm going to get my blood work on Wednesday. First time in a few years, because I haven't had healthcare. I'm going to find out how my liver's doing. Now, I can probably find out without getting a biopsy again, a little better what stage I'm at, too; because they have new ways of looking at the blood work. But how, if it's progressed; if I have cirrhosis; how could I treat it? I can't. And I'll be like a lot o' other people, who will just die because they don't have healthcare.

SS: Well then let me ask you my final question. Which is, given everything that ACT UP has achieved and struggled with, what do you think is its greatest achievement and what would you say is its greatest disappointment?

GC: Some of the greatest achievements, I think — well, having just talked about it — are the fact that we have needle access to a greater degree; that there is a greater recognition of substance use and alternatives to prison; although of course, that drug war bullshit still persists.

That we have changed the dialog with physicians; that it is your body, and your own self-empowerment, that will help you survive. I think that's an enormous outlook shift that ACT UP put out there.

That we've shown the spotlight on so many of the, the horrific problems that exist; in New York, in the United States, and in the world, from homelessness to, I did a lot of work around homelessness. I was sending e-mail, eh, faxes, early on, to Dinkins, every day, about the horrific situation, and he didn't do shit.

That we got the U.S. to back off — well of course, that was more Health Gap than ACT UP, but I still think of those as kind of sister organizations — Gore to turn around on that suit against the Medicines Act, and recognize that patents do not trump human life.

Those are some of the great successes. That there are twenty-some drugs now available. Unfortunately, that also ties in to some of our worst failures. Because we were unable, for example, I think, to really have an effect on the vaccines, the envelope vaccines, which are just an outrageous boondoggle. I remember, in '92, '93, looking at the data on these envelope vaccines, and they were a complete failure. And yet, millions and millions of dollars; and worse, many, many, many lives have been wasted on these worthless vaccines. I think if we didn't have a Congress, a Health and Human Services, NIH and FDA so thoroughly in bed with the pharmaceutical companies, we might have a vaccine by now.

I think there's evidence to suggest that we could have vaccines that elicit immune responses to the core protein of HIV, p24. I've thought this for a long time, and I think that might be more effective. But, A) money was there; and B) that's the way

they'd always done it; and C) this arrogance that exists in the government perpetuated this nonsense for many, many more years. And I think we have not made any progress whatsoever with the pharmaceutical industry, and to the contrary, they've just become more powerful, more belligerent, and more evil. And we fucked up there; we didn't have any success with that; and that's going to be the death of a lot of us.

SS: Okay. That's it for me. Thank you, George.

GC: Thank you, too.

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00:40:00

SS: Okay.

GC: Um, didn't really talk a lot about alternative stuff, though.

SS: Well –

GC: You don't care! {LAUGHS}

SS: We tried. I mean, do you want to say, is there something you want to say?

Jim Hubbard: – something else you wanted to say?

JW: Yeah. Also – you can always add more things when the transcript's up.

GC: That's an idea?

JH: Is there something you want to say now?

GC: Um – yeah. Could I just –

SS: Yeah, just talk. I'm just going to unplug.

JW: You have a minute before I have to get a new tape.

SS: You have a minute. Go.

SS: Go ahead.

GC: A lot of my work and effort has been around understanding, of, well, I started a new organization a few years ago. And we actually got a couple of NIH grants. One of the greatest ironies of my life is that some, a percentage of my income — which is not much — comes from the NIH. The Foundation for Integrative AIDS Research, or FIAR; our mission is to basically do clinical trials, as Jon Greenberg always wanted them done, on complementary, alternative medicine. And that is essentially my healthcare, as a person living with hepatitis C. And I'm hoping that my blood work next week will show that I have at least stabilized or slowed disease progression. And I take a lot of supplements; maybe about 15 or 20 pills a day, of things. Which is not, compared to a lot of people I know, but a lot more than other people are willing to do.

I use these interventions based on understanding the disease: that hepatitis C doesn't cause liver damage directly. The virus doesn't damage liver cells. It's the immune response to the virus that causes the scarring, fibrosis; that eventually, the scarring begins to come together, then –

Tape IV
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GC: So do I get a chance to read the transcript and I can make changes?

JW: No. Not that, but, no. Oh, go ahead.

JH: Did you want to ask that?

GC: Okay.

JH: You get to add anything.

GC: Add. Okay.

JH: Yeah. So footnotes, or clarifications, whatever.

GC: So everything I've – Okay, good. So –

JW: Rolling.

GC: Okay. So I am looking for my blood work to see if it's, if the types of interventions I've been using have had any impact. And what I'd really like to have, of course, are some clinical data to support using these types of interventions. Most of the interventions I'm using, including antioxidants and Chinese herbs, don't have a lot of clinical data to support their use. There are some. And – more often than not, I'm looking at what clinical data there are, and also how these types of interventions slow disease progression – or at least that's my hope. Again, based on the idea that the virus is not killing the liver cells, but the immune response to it is. And so can we slow down the inflammatory responses and help at least slow disease progression.

I think there's enough evidence and data to support the types of interventions that I'm using. Time will tell. So I'm my own "n" of one, as it were, in, of this kind of evaluation. What I can say is in the brief period that I did have blood work available and did have health insurance, and used it routinely, one of the interventions that I'm still using actually normalized my liver enzymes. So that's at least one surrogate marker sign that might suggest that these interventions are having some kind of an effect.

There are a lot of data to support the use of different types of botanicals and micronutrients and antioxidants. And I can only hope that FIAR has stimulated some other organizations to begin to look at this. As I said, we've gotten a couple of NIH grants to begin to evaluate some of these types of interventions, but it's a very, very tiny amount. But it's a start. It's a seed that I hope will grow into some kind of wonderful medicinal plant.

And that's enough.

JH And so how are these alternative treatments looked on in ACT UP?

GC: In ACT UP, it's, oh, it's a really wide diversity of opinion. I think a lot of people use them. It's funny, even some of the hardcore treatment activists that seem to be totally focused on drugs, many of them use some of the more arcane interventions. Carlton, my friend Carlton, used DNCB, even though we really vociferously disagreed with one of its big proponents, who is a denialist. That's the other thing, we didn't talk about denialists a lot, but – most of them are dead anyway, sadly. Unfortunately, so are a lot of our friends who were not denialists, so that's not an argument against them. The science is enough of an argument that says HIV exists and causes AIDS.

I still think that there is, I think there's less, actually, of a negative feeling toward alternatives, because we're beginning to develop more data. For example, at the recent retrovirus conference, there's been data coming out about fish oil and its benefits for triglycerides and cholesterol and heart function, for example. So those kind of data, I see that happening more and more, that there is more acceptance. Like AIDSmeds, Peter Staley's really marvelous — I want to say something nice about him, since I said something bad about him — he's done this marvelous Web site, where they have reported on these types of issues. And they're living with HIV. Tim Horn has done a lot of research on these kinds of things. And so there's more acceptance than there used to be; that these interventions can have a benefit, and that they can be clinically evaluated for their benefits.

On the other hand, though, one of the things that freaked me out about the retrovirus conference; for example, there was one drug called ezetimibe, which I'm pronouncing; it's E-Z-E-T-I-M-I-B-E; I don't quite know how to pronounce it. It's part of this two-drug combination called Vytorin, which is simvastatin. Anyway, they looked at just the ezetimibe drug, for cholesterol. And the big title of the presentation was, It helps with LDL! Whoop de doo!

Tape IV
00:05:00

And sadly, when you actually, when the researcher actually presented the data, how did it help it? About 12% reduction. Which the researcher himself, when challenged with this by some questioner in the audience, said, about the effect of a bowl of oatmeal. And yet, most of the AIDS information resources just recounted, it worked.

The same thing with an osteopenia drug. Osteopenia is the thinning of the bones, another problem that arises with antiretroviral drugs — or maybe HIV infection — which can lead to osteoporosis, which is serious problem. And they looked at alendronate, which is this nasty, horrible drug you have to take sitting up for half an hour, an hour, because it'll fry your esophagus if it gets up into there. And they compared it to use of calcium and vitamin D. And they found that the drug had a modest impact; and the calcium and vitamin D also was okay. It was kind of the drug worked better. Good drug.

But then — and nowhere does anyone talk about the dosages that they used of calcium and vitamin D; 500 milligrams of calcium, 200 IUs of vitamin D. And these are not the recommendations of the government! You should be taking at least a thousand to 1200 milligrams of calcium, if not more, and maybe 800 IUs of vitamin D. There's a lot more research coming out on vitamin D showing that it has good benefit.

And so again, here is research to show that this drug works better than practically a placebo? Well, duh. This is not research; this is garbage. What we really needed to know was, can you actually use these two safe, healthful, useful interventions instead of this horrible, expensive drug, and get the same benefit? And the answer, we don't know, because they didn't set up the study that way. They set up the study to sell the drug. And again, unfortunately, none of the major AIDS organizations — except AIDSMEDS, when I called them on it, on the ezetimibe study, and they changed, Tim changed it. He realized that it was not a good way to report it. But they basically have all become mouthpieces for Pharma. And it's kind of disgusting.

So again, that's, to my mind, the reason we need to have clinical studies of complementary alternative medicine is that we need to bring science back into healthcare research. And science has been destroyed by the pharmaceutical industry. They have taken universities and hospital research; they have taken the government research; and they have turned it all into marketing tools to sell more drugs to people that mostly don't need them. And the real benefit of drugs gets lost in the haze of bullshit.

JW: Well, it's a living.

GC: It sure is.

SS: Okay.

GC: That's it.

SS: Thank you, George.

GC: Thanks.