ACT UP
ORAL HISTORY PROJECT

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Interviewee: **Bill Snow**

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Interviewer: **Sarah Schulman**

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Interview of Bill Snow
April 16, 2003

00:01:04 BILL SNOW: My name is Bill Snow. It's April 16th, 2003, and my age is 55, and we're in Berkeley, California.

SARAH SCHULMAN: Do you remember the first time you heard the word AIDS?

BS: Yes, I think so. I mean, I can't pick a moment, but I know I was living here in San Francisco when the whole notion of this disease – this strange, unnamed disease – hit the gay press. So, I knew about it. Now, when it got its name, I'm not sure I could tell you.

SS: So, you heard about it before it reached your life or anyone you knew.

BS: Oh yeah.

SS: And, when did it first start to come close?

BS: Well, it sort of crept up on me, to be honest with you. I didn't really lose any friends in the beginning of the epidemic, because I didn't really have a lot of gay friends. But we worried about it, because we knew there was this disease out there, and it was happening to people.

SS: Why didn't you have gay friends?

BS: Why didn't I have a lot of gay friends?

SS: Yeah.

BS: I don't know. I guess I grew up in San Francisco. I sort of came out at a rather advanced age. I was about 26 when I came out, and I sort of kept the friends that I'd had prior to that, more than anything else. I never really had a terrifically active gay

social life, until AIDS, really. That was one of the advantages of getting involved in the epidemic, is that I met a lot of terrific gay people that way.

SS: So, who was the first person in your life that had AIDS?

BS: Well actually, I had an uncle who had AIDS, though he never talked about it as having had AIDS. My mother's half-brother and his partner, both, ultimately died of AIDS. But, he had a sick period, and he's probably the first close person that I knew. And then, some colleagues at work.

SS: So when that happened, what were the infrastructures in place at the time?

BS: Well, this was San Francisco, and in a lot of ways, San Francisco was the vanguard – in the beginning – of treating the epidemic. So San Francisco General was seen as the place to go, where people knew what to do about this epidemic. And there were a lot of doctors in San Francisco involved.

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SS: Do you remember your uncle's course of treatment?

BS: I don't. He had Lymphoma.

SS: And, what was your job at –

BS: It was way before there were antivirals. So, I think he mostly got treated for cancer.

SS: What was your work, at the time?

BS: I ran my own business. My skill is – I was a schoolteacher early on – and
00:05:00 my skill is adult education. So, I gave up school teaching in my 20s, and started working for corporations writing training programs. And, by the time AIDS came around, I had

gone freelance, basically. And I was designing and writing training programs for corporations and had been doing that for a few years. It's called instructional design.

SS: Had you ever been involved in any kind of political movement before this?

BS: Oh yeah. I was in Berkeley in the mid-'60s. So you know, I was a Berkeley student at the height of – not the Free Speech Movement – I came right after that, but the People's Park and the anti-war movement and education of – sending out minority studies programs and things like that. So, it was very much part of my college experience. It was half of my college experience.

SS: So, it was natural for you to – would you say – seek out other people in a time of crisis?

BS: Well, I think I understood about protest, for sure. Natural – no, it's not my nature to want to seek out people in a time of crisis, especially strangers. But I was actually so impressed with ACT UP when I first caught sight of it, that it attracted me.

SS: Okay, so why don't you tell us – how did you first come into contact with ACT UP?

BS: My partner Christian and I had moved to the East Coast. It would have been – here's where my sense of dates is so terrible – 1983, maybe? He could tell you. And by then, AIDS was much more of a well-known commodity. And we had a friend who actually worked on the staff of the Names Project – the quilt thing here, in San Francisco. And he invited us to come to the big protest in Washington, to help man the quilt, because it was the first time the quilt was ever displayed in its entirety. I think.

So, we were down there doing that, and ACT UP had a very impressive presence at that march. And we were living in New York, right around the corner from the meeting, so that was what sort of caught my attention.

SS: What was it about their presentation that grabbed you?

BS: Well, it was full of life. It was big. It was brassy. It was exciting. And it was right around the time when I found out that I was infected. So, a big part of getting involved in ACT UP for me was trying to learn about what I could do about my own HIV positive status.

SS: Okay. So, what happened at the first meeting that you attended?

BS: Well, I always felt somewhat out of place. I was older than your average ACT UPper by a chunk and in a relationship and had a business and more of another life that kept me busy. I think my first meeting would have been at the Gay Center and they were always, in the beginning, somewhat overwhelming. I mean, there were so many people and there was so much going on in this sort of disorganized way. I would go over and listen on whatever night it was. I can't even remember if it was Tuesday or Thursday or something like that. And hang out as long as I could stand it. And collect whatever materials there were. And I did that for a while. And then, what really interested me was the treatment stuff. So, I started going to the Treatment and Data Committee meetings fairly quickly, which was much more manageable than the general body meetings.

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SS: So, who were some of the people that you working with in Treatment and Data?

BS: Well certainly, David Barr and Mark Harrington. Now, here I'm having name aphasia again – the fellow who worked with Mark on the treatment access stuff, with the FDA.

SS: Peter Staley?

00:10:00 BS: No. He gave up activism, pretty soon afterwards. The one who's helped set up the FDA committees and stuff. You're not helping me.

SS: Sorry.

BS: David Barr was around – a lot of the people that I got to know much better, as I started doing work with the committee were there. It was a small, sort of clique-ish group. Nobody was particularly welcoming or helpful. Mike Barr, actually, was the most, sort of open person. He was writing the minutes of the meetings in those days. And he was, actually, much less sort of totally caught up in the work, and more sort of receptive to answering questions and being a little bit friendly.

SS: Now, were there a lot of people in T&D who also were HIV positive?

BS: Yeah, I think so. I mean, it never was a huge issue whether people were positive or not, in the beginning.

SS: Did you discuss your treatments with each other?

BS: There wasn't a lot of treatment to discuss. People were mostly getting sick and dying and what did we know about? We knew about PCP prophylaxis, and AZT – that was it. It was really before there was much choice in antivirals. And, mostly those people weren't sick, even if they were HIV positive. So, I don't remember a lot of talk about – it was not like a self-help group. It was very much a work-oriented situation, where people were trying to understand how to get drugs, and what it would take to test

the drugs that were out there and get them approved and get things for people – besides the few paltry things that were available – and to understand the system.

SS: So when you first came in, were you taking AZT?

BS: No, no. I was – I had high counts and I was in perfectly good health, I was just terrified because if you read the literature in those days, the projections were crash-and-burn in a couple of years. So, I tried to sort of get a handle on what, if anything, I could do, which was actually how I got involved in the whole vaccine issue, which is what ultimately caught my interest and became the thing that I really care about. And, I guess a fair way to put it is – Project Inform used to say – they probably still say, for all that I know – that you have to do two things: you have to attack the virus, and you have to boost your immune system. And at the time, and up until this day, there has never been a good way to boost your immune system.

SS: What were some of the early things that people tried?

BS: To boost their immune systems?

SS: Mm hmm.

BS: Oh God. See, here again, I'm having name problems. People did a lot of alternative medicine kinds of things. There were some drugs, but I can't even remember – nothing that anybody ever made much of a case for, and certainly, nothing that – you know, there was this stuff that people rubbed on their skin – this –

SS: AL-721.

BS: Yeah. DNCB, right. But, none of it made a whole lot of sense to me, so I didn't pay much attention to it. And it all sounded like either desperation or a crackpot medicine. And Jonas Salk had made the case – I discovered, fairly early on – that maybe

you could stimulate the immune system with a therapeutic vaccine, which was very interesting to me.

SS: Before we get into the vaccine stuff, I just want to get some more preliminary. Did you work on any other campaigns before that began?

BS: Yeah, I did. I was around when we got access to the ACTG. So, I went to
00:15:00 the first meeting that ACT UP ever went to, where people sort of barged into the meeting and demanded to be part of that process.

SS: Can you explain a little bit, for people, what that all is about?

BS: Yeah, sure. The AIDS Clinical Trials Group was, at the time, the only place where AIDS drugs were being tested, as far as I know. It was funded by the Institute of Allergy and Infectious Diseases at NIH. And it followed a strictly medical model. It was a professional group of researchers who conducted clinical trials on patients and didn't particularly have an interest in what the patients thought about any of it, let alone what their input might be. And I think Mark and some other people – David – became very interested in having access to what was going on, because there were a handful of experimental nucleoside analogs that were in trials, and we were trying to get them approved as fast as possible, and make sure that they worked, and have some input into the trial design, because it was the only way people could get access to these other drugs – by enrolling in these trials.

SS: And which drugs in particular?

BS: Well, ddI and ddC – the dd drugs were the batch that were coming next down the pike.

SS: So, how did you guys approach the ACTG?

BS: Well, a bunch of us just went. I can't even remember whose idea it was. But, I actually had a friend who was a doctor at Mount Sinai, and she had a colleague who was registered for the meeting who didn't end up going, so I had his badge. So, I was actually the only person in the ACT UP contingent who actually had a sort of fake identification that got me into the meetings. But, we went down on a bus, and we all stayed in a couple of hotel rooms. And basically, there was this sub-committee on statistics that was open to having activist input and maybe you've heard about that already, I don't know.

SS: No, tell me.

BS: There's a lovely woman by the name of – here we go again – it will come to me later – who ran this sort of statistical working group of the ACTG. And we actually were invited to come and talk to the statistical working group. That was at the very beginning of the meeting and we all came into this room, and had this very interesting discussion about trial design.

SS: Do you remember what some of the issues were at the time? About trial design?

BS: Well, the issue was always, in the beginning, what are the inclusion and exclusion criteria? What's keeping people from getting access to these drugs who need them? And that boils down to the way that the scientists restrict access to the trial. And it always was a big issue – was to make the inclusion criteria as broad as possible, and the exclusion criteria reasonable for people with HIV and AIDS.

SS: So, what would some of the exclusion terms be?

BS: Lab values or concurrent infections, or people who tried other experimental drugs. I mean, there was a whole list of things that the scientists thought

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00:20:00 didn't interfere with getting clean, pristine data that the activists wanted to open up, obviously. And, it made sense to the statisticians, I think, because they understood that real people in real life were ultimately going to take the drugs anyway, and you wanted to get data on the people who were going to be using them.

SS: So, in that first meeting, you felt that they saw you as a real person.

BS: Yeah. I mean, I personally – I was dealing with two sets of strangers, really, because I didn't feel like I had much in the way of relationships with the ACT UP

00:20:00 people either. So, I was sort of, and I've always been sort of in an interesting place between the activists and the scientists, because I'm a little bit older, and I'm more the age of the main AIDS researchers. And much more sort of analytical, by bent, than a lot of the activists were – excluding the Treatment and Data people, who were analytical to a fault. And, anyway, I was used to dealing in my work, with corporate types. So, even though I was a kind of weekend hippie, when I was a college student, I was perfectly comfortable in an academic or a scientific world – though I didn't know beans about science. I mean, I never studied biology, so that was all new to me.

SS: So, were you studying a lot at home? Reading a lot?

BS: Yeah. I mean, I always read what there was to read. It took me a long time to sort of catch on to the science at the level that it happens at science meetings. And that was an interesting process. We can talk about that if you want.

When you go to a scientific meeting, it's a very formalized dance, and the scientists basically make presentations to other scientists and they're very short, and

they're very formalized. They follow a certain format. And often, for a non-scientist, the only thing you can understand is the title, and maybe the conclusion, if you're lucky. So, we used to go – as the years went on, we went to a bunch of AIDS conferences, and learned how to listen to those talks. And what it meant was – for me anyway – was learning virology and immunology ass backwards. I mean, you know, it was starting at the cutting edge and not having any of the foundation. So, you'd end up with notes that made no sense and a list of words that were repeated a lot of times, so you figured you better look them up. And that was sort of how a lot of us learned our science. And I still have this feeling that there's some magical key to immunology that if I only knew, it would all fall into place.

SS: Let's go back to that first AZT meeting. So, you had a good experience with the statistics, and you were passing as Dr. Somebody with your badge. And then what happened?

BS: Well, there was a huge to-do – as there often was at ACT UP events – where one group of people wanted to do one thing, and another group of people wanted to do something else. And certain people were in, and certain people were out, and certain people – was so-and-so a spy? And, there was all sorts of all-night brou-ha at the hotel room about what were we going to do? We were going to sit into the meetings. We were going to barge in. What was the best way to deal with this? And, it was really before the leaders of ACT UP got to know the leaders of the research community, which was a huge advantage, once it happened, because then you could just talk to somebody off-line, and try to figure out what was going on. So, I think a bunch of people sat in on a

closed meeting on one of the ddI trials or something like that, and got kicked out and guards were brought –

SS: Were you one of those people?

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BS: No, I wasn't. I had this badge, so I was never exactly – and I wore a sports coat, so I went out of my way to blend in, basically. And someone named Dan Hoth was in charge of the network in those days, and he was someone impossible about the whole notion of letting people sit in on meetings. Somehow or other – I think Fauci finally decided that something had to be done. And they had made this plan to set up this

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Community Constituency Group, which is an odd name, and it was sort of a top-down organization where they – some people from ACT UP – I think, especially David Barr and Mark helped Tony set up this group that included a bunch of AIDS organizations and tried to be inclusive of all of the populations that were involved in the epidemic. And then, they sort of felt their way into becoming an organization, which then became the official public way that people could get involved in the network.

SS: Through the CCG.

BS: Yeah.

SS: What was your impression of Dan Hoth? What was your experience of him?

BS: I didn't have a lot of dealings with him early on. He seemed very uptight, anxious, not in control in some way. I think – like so many people that worked for Tony – Tony's pulling strings in the background and Dan was sort of a buttoned up kind of guy. I think when he left NIH – like a lot of those people – he certainly loosened up and

became a much more accessible person. He came to work for a biotech in the Bay Area, and I met him years later. We had a nice conversation.

SS: What about Fauci? That's a long relationship – the ACT UP/Fauci relationship.

BS: It is indeed, and I didn't really – Tony was a way up there person for me. I had no direct dealings with him in my early days at all. But, I was at a couple of meetings, where he came to ACT UP and talked at the meetings, and I listened. But, I got to know him much better, when I started doing my vaccine work.

SS: Was he considered an ally?

BS: You know, I wasn't enough on the inside of the people who were dealing with him to know. I think Mark and Larry Kramer have always both had very close and ambivalent relationships with Tony – each different, each very different. But, that colored the way the organization dealt with him.

SS: What was the personal process for you to decide to confront the government as a gay man with AIDS and tell them what you wanted them to do?

BS: Well, it sort of came naturally to me. I'm a pig for information, and I'm most comfortable when I know as much as I can about the thing that I'm dealing with. So, the only way for me to deal with anxiety is to learn everything there is to learn and confront people who understand stuff, and ask them questions and get explanations about things. And it was my work. I mean, I went into corporations and did that for a living, 50 hours a week. So, I wasn't shy about that at all. And I'm a quick study. That's part of one of the things I learned, when I learned to write training programs – was to learn about stuff that I didn't understand really fast, and get a grasp on it.

And I'd never really been sick. I had a doctor in San Francisco who I liked, and I always, you know, treated him sort of as an equal anyway. And we would discuss the little ailments that I had and he was a nice guy and I just sort of treated all the doctors that way – it never really occurred to me not to.

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SS: So, at this point, what was the relationship between Treatment and Data and the floor? Were you still going to the Monday night meetings?

BS: I did, yeah. And I would go and they'd last a really long time, and I would try and go at the time when the Treatment and Data part of the meeting was going on. It wasn't that I wasn't interested in the rest, but I had my limits, as to how much of that – it wasn't my social life, it wasn't my social circle. I didn't really have very many friends to

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hang out with at the meetings. So, I'd go and sort of stand in the back and listen and watch the process, more than anything else, and check out the guys, because there were a lot of very attractive young men involved in the organization. It was fun. It was always exciting. I have to say – more than anything else that influenced me was Larry Kramer's book.

SS: Which book?

BS: *Notes from the Holocaust*. It was one of the first things I picked up, soon after it came out, and I was just blown away by it. It was so well written and so spot on and so – just impressive in every way – that I just sort of held him in awe. It was just a magnificent piece of work. And I'd seen some of the articles along the way – in *The Blade*, and various gay papers. But, having them all in one place was really just sort of an overwhelming experience for me.

SS: Do you remember a particular concept or paradigm of his that moved you?

BS: No, I don't think it was conceptual at all. I mean, I don't think of Larry as a conceptualizer, exactly. I think of him more as – I'm sure you've heard this – like an old testament prophet – someone who can see how things are going to play out, and warn people about it.

SS: Did you relate to the Holocaust metaphor?

BS: Yes and no. You know, I'm Jewish and the whole idea makes me crazy and uncomfortable and sick, but it's not like it was a big part of my family life or anything. My family's been in the U.S. for a long time, and we didn't lose relatives, and I was born after the war. Actually, it's interesting because Christian, my partner, is Danish, and he's older than I am, and he lived in Denmark when it was occupied by the Nazis. And he's actually a convert to Judaism. It has a more sort of visceral effect on him than it does on me, even.

SS: Were you persuaded by Larry's arguments about genocide?

BS: No. I have to say, I don't think I ever felt like there was a conscious effort to kill off gay people. I think that the real problem was that we weren't visible – that the gay people in everyone's lives were not out in a way that made it easy for them to identify with us as an oppressed minority.

SS: So, did that make you change the way you related to your family or the people around you?

BS: Well, I've always – I mean, I grew up in San Francisco. I've always known gay people. I've always had gay people in my family. I had my own personal

issues about it, but it's not like they made me come out to my family. They knew I was in a stable relationship with someone that they knew and liked. I had this gay uncle that everybody knew.

SS: So, you never thought about hiding that you had AIDS from people that you knew?

BS: No, no, no. I never really – I mean, I didn't go around and tell a lot of people that I was HIV positive, but that was mostly for business purposes. You know, I was running a one-man business, and I didn't particularly want people not to give me work because they thought I was going to get sick tomorrow or next week. So, I was pretty careful about who I told. A lot of my friends were friends who I knew through my profession. So my family knew, and my closest oldest friends knew, but I didn't make a big issue out of it, otherwise.

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SS: So, what were some other of the campaigns that you worked on, before the vaccine project?

BS: Well, for me, the biggest thing was I went to Treatment and Data, and everybody was working on antivirals. It was the most exciting thing. And, it became very clear to me that that was a competitive enterprise, you know? That working on an antiviral was something where you had a big ego and a lot of push.

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And, there were lots of people who were working on those things. So I sort of looked to find something interesting, that I could work on that wasn't receiving much attention. And, actually, the first thing that I came up with was CML. I don't know if you know much about that at all, but it's a really bad brain infection, caused by another virus, and people were dying of it, really fast – not a lot of people, but it was one of the

opportunistic infections that was disastrous but not common. So, I did a bunch of research on that, and impressed the big shot T&D people that I could actually make a contribution, through that activity. And there still is no particularly good treatment for it, but the instance has gone way down with antivirals.

SS: Now, is there an issue about opportunistic infections that affected a small group of people? How easy was it or hard was it to get research track for something that didn't have a large consumer base?

BS: Well, you know, there were the big five – there were the ones that, you know, that the Countdown 18 Months program was aimed at.

SS: What were they – the five?

BS: Let's see if I can remember – PCP, CMV, Toxoplasmosis – my memory is not good, I'm sorry.

SS: Was KS still an issue at that time?

BS: Yeah, I think it was still an issue. But, I'm not sure it was one of the ones that Garance [Franke-Ruta] identified as ones where we could have treatment in 18 months, which was what that was all about.

SS: Oh, that was her concept?

BS: Oh yeah.

SS: Oh, I didn't know that.

BS: You didn't know that? Have you got –?

SS: We're going to, of course, interview her, but I haven't been there yet.

BS: But, yeah – I mean, the whole notion of that program was similar to having prophylaxis for PCP – could we get prophylaxis for the other, most common

opportunistic infections. And the rare ones did fall by the wayside. And the only reason that this one was of interest was that it was such a disaster. I mean, it was just a terrible, terrible fast-dying disease.

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BS: ...which was odd, because he was never particularly oriented towards that angle of stuff, but he used to come a lot.

SS: Do you think he came for his own treatment?

BS: No, I think it was – Larry's a really smart guy, and it was interesting to him. It was where a certain kind of action was in the organization.

SS: You wanted to tell a story about Garance.

BS: Yeah. I didn't know Garance well at all during my ACT UP days. But, when I became interested in vaccines, she also had an interest in that. So, she and I and David Gold started the AIDS Vaccine Advocacy Coalition. And I worked closely with her for a number of years, until she got caught up in college and having starting a career. For me, half of the fun of coming out to San Francisco has been hooking up with people I had seen in New York and sort of never had become friends with and getting to be friends with them – like G'dali and Garance, who never lived in California, but we did a bunch of activist work together.

SS: So, those are relationships that have lasted?

BS: Oh yeah.

SS: I want to ask you one thing before we get into the vaccine question – this is just something I was curious about myself. How large of a consumer base did

there need to be before a drug company would seriously pursue an opportunistic infection?

BS: Well, you know there's the Orphan Drug Law, which is something that had already been passed in Congress before AIDS came along, that gives incentives to companies to work on drugs for "orphan" diseases, which I think are defined as diseases with less than 500,000 people in the United States.

00:40:00 So actually the first AIDS drugs were orphan drugs. There were not 500,000 cases of AIDS, and the companies got the financial and patent benefits of orphan drugs, of which there are some real valuable ones. You can get – you get certain tax relief, but less important that, is that you get exclusive marketing for your disease for awhile, and it's stronger than a patent. So, I think AZT was an orphan drug, and ddI might have been an orphan drug, too, I'm not sure. So there was actually an odd middle ground of drugs that either, in effect, were really rare, like KS is a really good example – where there was never going to be enough of a market to have orphan drug status be advantageous. But, you know, there's a lot of researchers and like me, picking this really odd disease, there's somebody to work on everything, you know, because people like to work on something of value, and the high profile things get crowded. They're competitive.

SS: So, vaccines.

BS: Hence, vaccines.

SS: Right. How did this come to you?

BS: Well, I mean, I've always said that it was Jonas Salk, and I think that that's a fair assessment. Jonas wrote a paper in the late '80s I guess – mid-'80s, in which he proposed this notion that you could make a therapeutic vaccine against HIV, and that

was very interesting to me, because there was no – I don't know – I'm a child of the '60s. It was using your own immune system to fight off the virus, you know – it wasn't poison. In a way, I grew up with the discovery of the polio vaccine. It seemed like a way to go.

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And there were some people doing work on HIV vaccines around that time at Hopkins – Mary Lou Clements, I don't know –- do you know who Mary Lou was?

SS: No.

BS: Mary Lou was an important vaccine person. She had, you know, worked on Hepatitis B vaccine and a bunch of things. She ran a vaccine center at Hopkins. And, she was doing work – one of the early people who did work on HIV vaccines. She ended up marrying Jonathan Mann, and they were both killed in that plane crash some years ago. But, I think I heard about this work that was being done, and it sounded really interesting. And, the whole notion of a therapeutic vaccine – there was this Salk therapeutic vaccine which was whole, killed HIV, that they were giving to people in Baltimore. It was sort of a research phase for that sort of thing.

SS: That was the first?

BS: No, actually the first therapeutic vaccine was something call GP-160, which was HIV envelope made in insect cells, and it was, essentially, trying to do the same thing that the hepatitis vaccine did – genetic engineering of the outer core of the virus to create an immune response.

SS: And that was given to humans?

BS: Oh yeah. I was actually in an early trial of GP-160, as a therapeutic vaccine, at NYU.

SS: So, the vaccine was for people who were already HIV-positive?

BS: Oh yeah – the original idea. I mean, people thought that maybe a vaccine could do double duty – that you could give it to someone who was infected, and it would stimulate these extra, new immune responses that would help them stay healthy longer, before they needed antivirals. And there was actually a parallel of the ACTG. There was a vaccine AVEG – AIDS Vaccine Evaluation Group – that was looking at therapeutic and preventive vaccines together.

SS: That was NIH?

BS: Yes – that was started around the same time that the ACTG was started –

00:45:00 at five totally different academic centers. So, the wonderful thing that happened was, that after we sort of marched our way into the ACTG, the vaccine people got nervous and invited us to come to their meeting. So, ACT UP Treatment and Data Committee got an invitation to go to the AVEG meeting the next year.

SS: And who was there?

BS: I went. Mark went. I think Garance went. This is so terrible. There were about five of us who went to that meeting.

SS: And who were the researchers?

BS: Well, Jonas Salk was a big, hotshot research, Mary Lou Clements was a researcher; Bob Siliciano, who worked with Mary Lou. There was Robert Redford – there's another story – who was with the Walter Reed Group that did a big trial of this GP-160 vaccine with the army research. But, a bunch of us went to the meeting, and that meeting was sort of, for me – the light bulb went off about preventive vaccines – that, you know, here's this disease: it's incurable, the drugs are horrible, people are going to die sooner or later with or without the drugs. What you really need is a preventive

vaccine to stem this epidemic. And I just became very, very interested in that. Plus, the science was really different. It was immunology instead of virology, and it was challenging and exciting and more open. Drug development is a highly competitive, not all that academically rigorous enterprise. Basically, you try a lot of things in a test tube and see what kills the virus, and then you try it in a mouse – a hairy test tube. And then you try it in people, and if it works, it works.

Later on, people started talking about rational drug design. But, it was never a scientifically very interesting thing. They were just recycling old cancer drugs in those days, and putting them in a lot of people and seeing whether more did better than got sick from them. And, vaccines was really interesting. It was easy to tell the difference between the level of science that was going on in a vaccine meeting, than in a NACTG meeting. It was like night and day. The people were more collaborative. They were puzzling out a very complex, difficult problem, and they were more open, in a bunch of ways.

Tape II
00:10:00

SS: Why do you think that was?

BS: Well, I think that it wasn't a commercial enterprise in the same way. I think there wasn't the same sense of urgency and panic about getting something. And, I think that immunologists are just more interesting than virologists. I mean, I don't know how to say that, exactly, but there's something about the immune system and how complex it is, and the way the body fights off an invader that's very interesting, scientifically. So, I had this sense that it was much less of a political battle to be an activist in that world, than it was to be in a world where people were either trying to make a lot of money off of their products or win a lot of prestige by being the chief

investigator of a big trial. People were really trying to puzzle out what the virus was doing in the body, and why the body wasn't able to fight it off. And it just was fascinating.

So, that got me interested in vaccines and in immunology. I mean, I was never much of a player in ACT UP. It wasn't my intention. I wasn't particularly interested in
00:50:00 either the social side of it or the glory side of it, but I wanted to do something. And so, pretty early on, I hooked into the idea that somebody at ACT UP should be paying attention to the vaccine part of the enterprise, and that became my thing.

SS: Did you have any trouble persuading other people of the value?

BS: No. AIDS activists totally get it. There has never been – reporters often say, "Well, what about the conflict between treatment and prevention, and what about the …" – AIDS treatment activists get it, you know? They really do. And people with HIV get it, because having HIV is something you really wouldn't wish on your worst enemy. So you know, occasionally, there's fighting over funding and stuff, but it's pretty much been – you know, you can have a bigger pie, rather than trying to cut the pie a different way.

SS: Can you tell me about the campaign? How you began and what happened?

BS: Well, I worked with Treatment and Data, and started going to the vaccine meetings and helped the vaccine trials unit set up, basically, community boards at the sites. It was unlike the treatment CCG. It was a bottom up operation. And someone named Peggy Johnson was in charge in those days, and she's in charge again. She left and helped to find IAVI and then came back to NIH.

SS: What's IAVI?

BS: International AIDS Vaccine Initiative, which is a non-governmental organization funded by, largely, the Gates Foundation, but also a bunch of European governments, and some U.S. money, to develop a preventive AIDS vaccine for the developing world. And, it was set up when nobody was working on that. It sort of came into being around 1996.

SS: So, the preventative vaccine campaign very much coincided with the realization about global AIDS?

Tape II
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BS: Oh yeah. I mean, it came to the forefront, really, at the AIDS conference in 1996. I mean, the AIDS conference in '96 –

SS: Which was one that? Where was that?

BS: It was the one in Vancouver. People got – it was when this whole notion of eradicating HIV was in the spotlight, and David Ho was the big hero, and people thought we were going to all get cured with drugs. And, the problem with that, of course, is how expensive it is – besides the fact that it turned out to be a false hope. The international AIDS meetings were always international, and there was a whole set of people who realized that even if you could eradicate HIV, there were going to be millions of people who couldn't afford to get cured, basically, and it was the whole notion that you're not going to stop this epidemic by curing the people who are infected – sort of came to the forefront. And I got that early on. And people got it, but it didn't sink in, in a real way, until '96, which was a long time into the epidemic, when you think about it.

SS: Why do you think it took so long?

BS: I think because there's no constituency for the at-risk, in the same way that there's such an active constituency for the at-risk-of-dying crowd. And, so much of it went into behavioral intervention. So much of the effort to stem the epidemic went into the social sciences – that the idea of a biomedical intervention was sort of an out-lyer and it fell between the cracks.

And it's still just an idea. I mean, we don't know that there's ever going to be a preventative vaccine for HIV. We are pretty sure that it's doable. And I believe there will be one some time. The science seems to justify it. I mean, you can make one for monkeys, so there's no reason why you shouldn't be able to make one for humans.

SS: Where is it right now?

00:55:00 BS: Well, there's a ton more money than there was in 1996. There's an active cadre of researchers. There's a bunch of, actually, industry players for the first time ever. The vaccine business is not a good business. As medical businesses go, it's not a good business. People expect to pay pennies for a vaccine, and they expect it to be 100 percent safe. So, it's a tough racket to make money in. And, there are only four or five real vaccine companies left in the world – when there were 20 or 40 a generation ago. They've all sort of either consolidated or they're little withered arms of big drug companies. So, there's candidate vaccines. It's very hard to know what's going to work, unless you run an efficacy trial, because there's no correlate of immunity. We don't know what would be protective. So, people have notions that if we can get a certain amount of antibody or a certain kind of cellular response, it would protect a person from infection. But, they're inadequate models for knowing what's going to work and what's not going to work. And the only ethical way to find out whether something's going to

work or not is to put it into thousands of people at risk, and then wait and count the number of infections between the placebo and the vaccine. So, it's a very expensive, very time-consuming trial and error process.

SS: But how would you ethically accrue human beings for a trial for a vaccine?

BS: Well, there's no real problem about that, because you counsel people. You do testing and counseling on a regular basis. You do everything that you can to keep people from taking risks, and they still take risks. So, it just means you have to have a bigger population. In order to get 50 infections, you've got to go somewhere, where there's enough background HIV and enough risk-taking, so that you know you're not going to reach everybody.

SS: But, have there been human trials?

BS: Oh yeah.

SS: Where was the first?

Tape II
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BS: Well, there's only been one efficacy trial. There's been dozens of phase one trials, a handful of phase two trials, which are done in people who don't have to be at high risk to look at the immune responses of certain vaccine candidates. But, the only one that made it into an efficacy trial was this VaxGen GP-120 vaccine, which is a really an interesting story. VaxGen is a spin-off of GenenTech. And GenenTech invented this vaccine, as did Chiron invented a very similar vaccine, way back in the '80s, that was basically modeled after the Hepatitis B vaccine. It's this envelope protein that you can genetically engineer. There's no live HIV in the process. So, it's totally safe. It's how the Hepatitis B vaccine is made. And you get antibodies to the vaccine fairly easily, in a

very high percentage of the people. So, in the late '80s and early '90s, that was where all the vaccine research was focused, and people had high hopes for these vaccines. And, it all came crashing down in 1994, when we discovered that the anti-bodies that they were raising were not relevant antibodies – that you could prevent infection in a chimp, but chimps don't get sick.

And, basically, the only antibodies that you could raise were antibodies to lab strains of HIV – not to wild HIV. So, NIH, essentially, refused to run an efficacy trial of GP-120, and Chiron went out of the business and went back to reformulating for a better antibody-inducing vaccine and GenenTech tried to drop their product, but Don Francis was working for GenenTech in those days, and basically, Don said, give me the right to test this product. I'll start a company. So, VaxGen, this company in South San Francisco is Don Francis's – you know who Don Francis is –

SS: No, I don't.

01:00:00 BS: Oh, Don Francis is the hero of *And the Band Played On*. He's the main CDC character in the Randy Shilts book, who screams about AIDS when it's brand new and nobody listens. He's a culture hero of sorts, in the history of AIDS. And Don has always been a great believer in preventive medicine. And he found a really smart venture capitalist and they raised the money to run this efficacy trial, privately. And it just ended. It just had its unblinding of its results, and it didn't work – which is what most of the scientific community thought was going to happen. But, it proves that such a trial can be run. It was run on 5400 gay men in the U.S. and Canada and Holland. And they enrolled the trial in a reasonable amount of time, and they had more infections than they thought

they were going to have, and they know with scientific certainty, that the vaccine was not effective.

SS: Do you think it effects people behavior to know that they have been, have received a potential vaccine?

BS: I think it effects some people's behavior. It effects, certainly, some people's decision to participate in a trial, and there's nothing you can do about that except warn people and tell them, they're not going to be protected, and that they are as likely to get the placebo as the vaccine and that the only reason to really do it is for altruistic reasons. And that there will always be people who have been taking risks anyway, and who figure it's worth a try, and that they think it's going to – there's an outside chance that it might work and it might help them and they're going to do it for selfish reasons. But, there's a lot – not a lot – but there's a fair amount of research that actual risk behavior doesn't go up in a vaccine trial, it actually goes down a bit – reported risk behavior, because people are going in on a regular basis, and being reminded and all that sort of stuff – getting extra education and extra testing.

Tape II
00:25:00

SS: Right, and they know that somebody cares.

BS: Exactly. It's in the forefront of their thoughts in a more regular basis than it would be otherwise.

SS: I'm going to say this very simplistically, because I don't have the depth of understanding that you do, are you saying that a vaccine is a potential way to end AIDS?

BS: Oh yeah, it's the only potential way to end AIDS. I think, if you talk to any epidemiologist – anybody who studies infectious diseases – they'll tell you that no

disease has ever been eradicated except smallpox. And smallpox was eradicated by a vaccine. And polio has been almost eradicated from the world by a vaccine, and the reason is fairly simple, it's that there's something called "herd immunity" – there's a level at which the disease becomes so rare that it burns itself out. And AIDS is way beyond the point where that's going to happen through changes in behavior.

SS: So, you don't follow the theory that – and there are so many theories about the origins of AIDS – it was across the board immune deficiency, as a consequence of too much inoculation and medication?

BS: Yeah. It's a virus – it's a zoogenic virus, that crossed over from primates to humans, several times in the last 40 years. And we know that. We know that with as much certainty as we're ever going to know anything.

SS: So, what would you say is the impact of ACT UP on the development of a vaccine?

BS: Well, I think it's only indirect. I mean, several of us who got our start in AIDS activism, took an interest in vaccines and helped to start a vaccine advocacy movement, which has grown, not enormously, but which has grown. And, we were people who were active in the treatment and data part of ACT UP. I mean, that's David Gold and Garance and me, basically. And, we've since enlisted a bunch of people and
01:05:00 mentored a bunch of people, and now there's another constituency now. That's not to say that the AIDS treatment people aren't interested. Mark is still very interested. TAG is interested. GMHC is interested. Project Inform is interested. I mean, there's a definitely – the people who care about treatment, also, at some level, have an interest in this effort. But, it really didn't take off until after TAG spun off from ACT UP.

Now, out here in California, we have ACT UP Golden Gate and ACT UP San Francisco, and when I moved here, which was in '91 – I moved back – I started going to ACT UP Golden Gate, which was much more treatment oriented than ACT UP San Francisco, even in its pre-Michael Petrelis days – and just continued my work on vaccines and used it as a way to keep up on treatment advances and activism.

SS: So, what organization are you most involved with now?

BS: Well, I helped to start something called the AIDS Vaccine Advocacy Coalition, which is – now, is actually a going concern. We started it in 1995. We got, basically it was five volunteers – me and Garance, and David and a couple of friends of ours – Sam Haver, David Barr's partner, was one of them. And Chris Collins, who's now the Executive Director of AVAC. And we'd get some money from Until There's A Cure, the people who sell the AIDS bracelets, and did a very Treatment and Data-ish thing, where you did some research and published a report and got some publicity about the lack of industry involvement in AIDS vaccines. And, managed to raise enough money to hire a part-time, administrative person. And now we've got a little bit of a staff. We have an Executive Director and a science person and a community outreach person. And, slightly stable funding. We have money from the Gates Foundation that we just got. And from the Ford Foundation.

Tape II
00:30:00

SS: They're paying for this project also.

BS: Gates?

SS: Ford.

BS: And Until There's A Cure still supports us, and it's a small but very well known organization. And, I still do work with them.

SS: One of the questions I've been asking old ACT UPpers who do have AIDS – since we are making an historical document now – would you be willing to tell us what medications you're taking?

BS: Yeah, sure. I take five antivirals and a couple of prophylactic things. The most interesting part of my regimen is that I take T-20, and I've been on a T-20, as a trial participant, for the last 3.5 years. So, I'm probably one of less than 50 people, who've taken T-20 for that long of a time, and it essentially saved my life. There's no other, sort of less dramatic way to put it. I had wasting. I had real serious health problems and had never been able to bring my virus load down terribly far. And, through a series of lucky coincidences, I was able to start T-20, and non-nucleosides at the same time, in this trial that was set up to see what happened, when somebody started two new classes of drugs at once. And, it did the trick. I've had an undetectable viral load ever since, which is totally amazing.

SS: So in one day, what do you take?

BS: Well, the number of pills has actually gone down, because we played around with my background regimen. So, I take Kaletra, which is a combination, and I take Abacavir and Sustiva – so there's your four right there, and then, the T-20 – I give
01:10:00 myself an injection twice a day.

SS: So basically you're one of those people from ACT UP who saved your own life?

BS: Yeah, it wasn't always good news. I also enrolled in an early protease inhibitor trial that made me resistant to protease inhibitors. So, I took a chance and completely screwed up the chance to take triple therapy, in a way that made sense –

before people discovered triple therapy. So, I won one and I lost one. And, I was in the vaccine trial that didn't do anything to anybody.

SS: But, you were willing to take the risk?

BS: Yeah, and I've always been eager to – not experiment – but to jump rather than not jump, when the opportunity arose.

SS: I have just one last question for you. What would say was ACT UP's greatest achievement, looking back?

BS: Oh Lord. Well, I honestly think that ACT UP did more than any other organization to change the way patients and doctors deal with each other – that, the whole medical system has learned from the aggressive, white, gay man, who went in there and pushed, that it's a collaborative enterprise, and that doctors don't have the answers to everything, and that they're flying blind – like the *New York Times* says – 50% of medicine works, but we don't know which 50%. And, it sort of changed the whole decision making process, and the whole way the healthcare system operates. And, you know, it's crashing all around us. But, it's crashing around us in a different way than it would have otherwise. And I think when it gets put back together again, it will get put back together in a better way, because of that.

SS: You're always forward thinking. Thank you so much, Bill.

01:12:28 BS: Sure, it's been fun.