ACT UP
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Interviewee: **Sean Strub**

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Interviewer: **Sarah Schulman**

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SARAH SCHULMAN: Are you ready, Jim?

JIM HUBBARD: Yeah.

SEAN STRUB: Jim, that's your water if you want it.

JH: Okay.

SEAN STRUB: Do you want to close that?

SS: Do you want to close the window? It's **pretty noisy. There**'s **that machine.**

JAMES WENTZY: I'm not sure.

SEAN STRUB: Yeah, just open the little shutters and you can just push it down.

JW: This one?

SEAN STRUB: I don't think the center one is open, but you might just.

SS: So just look at me, and we'll start with your name, your age, today's **date, and where we are.**

SEAN STRUB: I'm Sean Strub. I'm 56 years old. It is Tuesday, September 30th. And we are in my living room, in Milford, Pennsylvania.

SS: Formerly the resort capital of mid-19th-century America.

SEAN STRUB: A resort capital, yes.

SS: Yes. And it's **2014. And thanks for making the time for the interview.**

SEAN STRUB: And Alfred has now joined us.

SS: Oh, great. So as you know if you've looked at any of the interviews here, we start with the beginning. So where did you grow up?

SEAN STRUB: I grew up in Iowa City, Iowa – a university town. Was the third of six kids. My dad's family had been in business there for a long time. I grew up in very Catholic background.

SS: Was that typical for Iowa City in the '50s?

SEAN STRUB: I was born in '58. So my real sort of conscious point of, decade of reference, would be the '60s. But there is a very strong Catholic community there. But it was a university town, so really dominated by the university. When I was growing up, there were fifty or sixty thousand residents in Iowa City, and close to half of them were students. So the university was kind of the dominant cultural environment.

And my family as – grew up Catholic. A lot of our sort of social milieu wasn't necessary with the parish, because of where we lived; we lived very close to the campus.

SS: Was your family connected to the school?

SEAN STRUB: My mother's guardian — my mother was orphaned as a two-year-old — and her guardian was the dean of the dental school. So she kind of – she spent part of her childhood in Iowa City, and was sort of connected there.

SS: So you don't experience that person as your mother's **mother; you experience them as a guardian.**

SEAN STRUB: It was her uncle, actually, and he died when I was six or seven years old. But yeah, I don't experience my mother as having parents, except people who died in the early 1930s.

SS: Oh wow, okay.

SEAN STRUB: And she actually grew up not having anybody she called Mom or Dad. She didn't have a maternal or a paternal figure. From the time she was two years old, she was in various orphanages and being fought over, in convents and things.

SS: So how did that play out in the family?

SEAN STRUB: That's very interesting. I think that's something that I and my siblings are still trying to sort out. It's funny, amazing; you come right to some sort of intense stuff that's sort of circulating. She died a couple years ago. And so in the years after a parent dies, I think it's probably not unusual to spend a lot of time thinking about the person. And she was socialized as the youngest of the little O'Brien orphans, because she was so young, and she had four older siblings. And I think that sort of shaped her personality, and that trauma. And I don't think I really had – enough appreciation of that, until the last 10 or 15 years, when she started to become sick, and I was sort of more into middle age.

But yeah, I think that was – very defining.

SS: But do you think that you were raised with an attitude about loss?

00:05:00 SEAN STRUB: No.

SS: No.

SEAN STRUB: No. I think I was probably protected from the concept of loss. She rarely spoke about her childhood – more so in later years. But growing up, didn't. We knew it was like this tragedy; that there was this awful sort of thing. But no, I don't think I had any particular consciousness of loss.

SS: So was your family particularly community-oriented, in relationship to the church? Like were you raised to be accountable to a community, and do service?

SEAN STRUB: I don't think especially so. My father volunteered with some things occasionally, but not in the sort of avid way that I saw others. There was definitely sort of a sense of being part of a community, more so than being accountable to a community, if that makes sense. I think they saw people who did good works as a good thing. But I didn't think of my parents as like especially active or committed volunteers in any sort of capacity.

SS: Well I mean, Iowa City was a famous progressive center.

SEAN STRUB: Right.

SS: And so in a way, you had a front seat to the '60s –

SEAN STRUB: Right.

SS: – growing up in Iowa City. And so was there like a town-gown split, between –

SEAN STRUB: I think there was. I don't think – I think that's maybe where our situation was a little bit unusual. Because St. Mary's Parish, which is right

near downtown, which is where my father was baptized, my parents were married, my grandfather was baptized there, my great-grandfather was baptized there; there's like this really long family tradition. My father's paper route as a kid was all around there; they lived a couple blocks away; their store was a couple blocks away. And we didn't live there. We lived on what was called Manville Heights, over near the university hospital.

And I think that that move – and also, my father married my mother, who was – went to church, was not active in the church; and we sort of socialized in a different way. We didn't really socialize that much within the parish. And I long recognized that one of the most fortunate circumstances of my birth was the zip code where I was born and raised. So the schools, the public schools in a university town in the Midwest in the 1960s and '70s were really pretty exceptional.

So I guess I was conscious there's some sort of town-and-gown thing. There were people you thought of as townies, and people you thought of as the U-High kids. And we were sort of neither or both. I didn't feel that division.

SS: So how did you start to conceptualize your future?

SEAN STRUB: As a kid, I almost never thought about a future. That was something I kind of came to realize when I was writing *Body Counts*, is that as a kid, I didn't – I knew other people had expectations of me. Oh, Sean's going to be a lawyer, or Sean's going to be a businessman, or Sean's going to be this or that or whatever. But I didn't ever, I don't think I ever felt like my childhood was a staging ground for something else. I was very entrepreneurial as a kid. That was something I

learned; that both I was skilled at, and it brought me attention within the family, when I couldn't compete in other things. I wasn't athletic, I wasn't really good at other kinds of things.

And – I think at some point, I sort of just came to assume that I would leave Iowa City; that whatever the future was, it wasn't there. I didn't see a role for myself in my father's business. I knew from a young age that I wanted to travel. I think I had that sort of instinctive sense that I needed to go somewhere else, even if I couldn't articulate what it was I was looking for. I jumped at the opportunity to go away to a boarding school, when I was 13, to a Jesuit boarding school. And that was very sort of a before-and-after moment for me, where I felt like I went out on my own.

00:10:00

Going back to one of the consequences, I think, of my mother's childhood is I think our family dynamic was atypical for our neighborhood, because my parents were not doting, overprotective parents. My mother grew up with this incredible independence, and without anybody sort of tending to her in that way. And I tell people that we had a coin-operated washing machine in our house, and the kids all did their own laundry, and people find that surprising, but that was normal to us.

My parents were very open and welcoming. Our house was where people always hung out. You could come home, and never know who would be on a couch, or who would be somewhere, somewhere, I don't know, playing, or whatever. So there was never any sort of discomfort at kind of being there. It was a very comfortable place. But my parents had their own lives, and were not that engaged in or attentive to their kids' lives.

SS: What did your siblings end up doing?

SEAN STRUB: My oldest sister was in the Air Force for many years. And then retired from the Air Force, and came to Pike County, and she was our elected county auditor, finishing her second term, here in Pike County. My older brother owns a plumbing and heating contracting business in Iowa City. And my younger brother just quit his job – he's moving with his wife to Spencer, Iowa, where she is going to be managing a Sherwin-Williams paint store. And then my younger sister, Gilbey, is a lawyer in London, where she's been for a long time – and gay. And my youngest sister, Megan, who was the publisher of *POZ* for many years, is now working for Dr. Oz's online web something or other.

SS: Oh, good. So the Jesuits. So I'm assuming that was a big influence.

SEAN STRUB: Uh – it was. This was at a time when the Society of Jesus was going through really intense upheaval. I don't know how much you know about Catholic orders, but the Society of Jesus, the Jesuits, are generally, like, the teachers. They're not typically parish priests. They're not especially pastoral. And had sort of a reputation for intellectual rigor and tough academics, and all that sort of thing. Which is what I think my parents expected, where they were sending me.

But actually, the school I went to was in kind of its last gasps of viability; and having been there for a hundred years, and having exemplified that sort of strict disciplined Jesuit tradition, and turning out lots of graduates who went on to various important things; this was 1972. So there was a younger generation of Jesuits,

who were sort of in the vanguard of change within the Church, and were very far to the left.

About three years before I got to the school they had thrown out the Junior ROTC program, because a group of the Jesuits had threatened to leave. And by this time, the orders were already declining. So they had, they were really reliant on these young Jesuits who had come in and teach kids who weren't that much younger than they were. A lot of my high school teachers were 20, 21 years old, 22 years old.

The first day – I mean – one teacher went to jail for running guns to Native Americans at Pine Ridge. There was another teacher who actually died of a heart attack while being held hostage by Natives at Pine Ridge.

SS: Wow.

SEAN STRUB: The first day of my freshman social studies class I remember to this day. I've been kind of wondering if I'd hear from him, because I had mentioned it in my book — he was a Jesuit scholastic. So you entered the order, and it was seven or eight years before you would become ordained a priest. But in that time, you weren't, you were still Mister, you weren't Reverend; but you had SJ after your name. Which indicated you were in the order, but not yet ordained.

00:15:00 And the teacher was a guy named Hal Dessell, Hal Dessell, SJ. So he was a scholastic. He was probably early twenties, I would guess. And the very first day, I remember, he was wearing a turtleneck, and he had a little bit of a beard, almost a Lenin-like beard. And he said, Good morning, gentlemen. He says, my name is Hal

Dessell; I am your teacher. And I am a Marxist. You may call me Mr. Dessell. And if I am a good teacher, at the end of this semester, some of you will be good Marxists.

That was literally the very, very fir-, I didn't know what a Marxist was.

And the first time I ever saw gay male pornography was from the algebra teacher, Father Kidd. So it was a pretty –

SS: Was that a private showing?

SEAN STRUB: It was kind of a – I think it was sort of a test. He was a prefect in one of the dorms. Another one of the prefects, who was then a scholastic, is now president of Boston College, Bob Leahy.

There was actually an article written – so I ended up graduating a year early, because the school announced that it was closing. Which had to do with the presidential campaign, which is another whole story. So a school that had been there for a hundred years, with this incredible tradition, ended up closing somewhat abruptly. And I remember Brother Gill, who was the school's treasurer — and some of the students were really furious about it, we were really upset — and explaining, you know, showing what the deficit was for the province to run the school. And to turn out – there were 68 kids in my high school graduating class, and a number of us were juniors, we were graduating early. And he said, for the school to graduate 60 or 70 students a year, and have, you know, maybe six or eight of them enter the order, and maybe one of those ends up getting ordained; versus they could spend the same money, and educate 10,000 students in South Korea, and end up with a thousand priests, or

whatever the number were – some very dramatic – it was a very corporate kind of decision.

SS: Plus, weren't the Berrigans Jesuits?

SEAN STRUB: Yeah.

SS: So Jesuits were getting a bad rap, right? I mean, they were making trouble for the Church.

SEAN STRUB: Oh, very much so.

SS: Yeah.

SEAN STRUB: Oh yes, yes. And in fact, like, Dignity, the Catholic – which I've never been part of; when they were kicked out of churches, they could still meet – and there were a few Jesuit – would actually have a church, they'd have a chapel at a school or at a hospital that would be controlled by the Society of Jesus, which is this distinct order; which was the only order that then did not report directly to the pope. It had its own superior general, Pedro Arrupe. And then one of the popes ended up changing that, after hundreds of years, to get the Jesuits in line. And when that changed, then the Jesuits couldn't even allow Dignity to have the masses in their facilities, as well.

And actually, the pope we have now is – is he the first Jesuit pope?

JW: Um hm.

SS: Um hm.

SEAN STRUB: I think he's the very first Jesuit pope ever, yeah.

SS: But you skipped the part about why the priest showed you gay male pornography.

SEAN STRUB: He was a peculiar priest. Who wore the same t-shirt every single day, a campy high school teacher. And the only time he put on his Roman collar was when he was going into town, so he could get the discount. And he had gerbils and guinea pigs that ran – and he was in a dorm room, so the prefect room at the end of the dorm. And he had a little gate across the doorway, and these rodents would be running around in his room loose all the time. And you'd go in there for your homework, or whatever. And he was sort of famous for giving tests that were impossible to do, that no one knew how to do them, and it was basically, you had to go in there to get tutored by him in order to get through the test. And you'd always heard these things about him, that he was grabby, or that, you know, the porn thing, I had heard. And maybe on some level I sort of knew that I'd heard that there was porn.

And the door to his room was open. I mean, he never made a move on me. But he was looking for something. And he opened a drawer. And he said, "oh, look in there, see if –" you know, whatever it was we were trying to find it's in there. And it's like, you know.

SS: So do you think he knew you were gay? Or do you think he just did that to everybody who was cute?

SEAN STRUB: No, I think he – he might have suspected I might have been. I didn't know that I was. I mean, I wasn't in a consciousness about it. But I think he probably did that pretty routinely.

I mean, there were – this was a school where there were teachers selling

00:20:00 drugs to students. And most of the faculty, they were in their early twenties. It was a really peculiar dynamic. And I ended up not having much high school, because I didn't have any senior year, and the second semester of my junior year, I was a page in the Iowa legislature; and the first semester of my junior year, I left about two-thirds of the way through, to go to Europe on a thing. So I had very little high school. And what I had was not very traditional.

SS: So when did you first know that there was a gay world, besides the drawer of this priest?

SEAN STRUB: Well, I remember that whenever David Reuben's book came out — *Everything You Always Wanted to Know About Sex: But Were Afraid to Ask* — and my parents had that, under the mattress. And I remember reading those passages specifically. And I suspect I must have looked them up, because I don't think I read through the whole book. And I was maybe, you know, this was – we could find out — but it was within the time that that was still in the news, so within a year or two, probably, after it was published. And I guess around 1970 – 1969, 1970, so I was 11 or 12 years old.

And then, in junior high school, about the same time, maybe '71, I remember looking up homosexuality in the card catalog at Central Junior High School; and terrified that Mrs. Casciacca was going to know what I was looking for, pulling open the "H" drawer.

So I was sort of conscious of that. And then, I think I remember reading in the *Des Moines Register* about the Stonewall riots. But it's like, one of those things that I'm not – I wanted to go back and find a microfiche and look at the page, because I think I even remember where it was – on an inside page, on the upper, on the left-hand page, on the upper right column of the page. So somewhere, something got imprinted there.

And then, the Gay People's Union at the University of Iowa, GPU, would – with posters around town. And there was sort of a head shop that turned into a nice gift store – kind of cool stuff, called Things and Things and Things, in downtown Iowa City, that Marcia and Tom Whiteman owned. And I used to hang out there, and they would hire me to run errands and help clean up, or whatever. And there were people there who, at the time, I was like pretty sure they were homosexuals.

And then I became aware of the Gay People's Union, and there'd be occasional literature around town and I'd see it. And then they had dances at the Unitarian Church — thank God for the Unitarians — and I can remember — this would have been, I'd just gotten my driver's license, which was when I was 16, so May of 1974. And it was literally within weeks of that, so it was like a spring dance or something, that the Gay People's Union was having a dance at the Unitarian Church. And I went down to Iowa Avenue. Where, I had previously, I knew they had meetings there, because I previously had been there, across the street, practically hiding in bushes, watching to see who went in and out. But I remember parking my car there, and watching people going into the GPU dance.

SS: So when did you first make contact with the gay world, or with other men, or –

SEAN STRUB: Well, there were several abuse experiences. And in one case, I knew that person was like a gay person, right? One, I didn't identify them as a gay person. And they probably never would have themselves, either. He was an usher at St. Mary's, and he was my algebra teacher, or he was my geometry teacher in seventh grade. And then the other was at the boarding school. And he was the one who I knew, I thought of, as a gay person. Or maybe that was just my evolution, and sort of understanding something then, or not.

And I saw him for years, first as a gay person, and second as somebody who abused me. Even though I didn't recognize it as abuse at the time.

But it happens a lot with sexual abuse stuff, is sort of that, you know, appreciation of the attention and that interest, and that sort of learning about yourself, and then, you know, become vulnerable and becoming, you know, damaged in some way.

But the first time – it really wasn't until I was in Washington. I went
00:25:00 into a gay bar in Paris once, when I was 16. All by myself. I'd left the little school group that I was with, and I found rue Sainte-Anne, and Club Sept. How I found it, I don't remember. I don't know how I knew about it. And I went in there, and was just like kind of terrified. They didn't card people; if you were 16 you could go in.

And I remember, somebody bought me a rum and Coke. And I'd never heard of putting alcohol in Coca Cola. It was like – and I didn't drink much then, or since.

So that was the first time I remember going into a gay bar. But then, when I moved to Washington, in early 1976, when I was 17, it wasn't long after that that I started going to gay bars in Washington, and meeting people, and having like friends that were gay.

SS: Before we get to Washington, I just have a question about what insights you have, having had this classic priest-boy experience, but in another era. Do you have any insight into this phenomena that's become so huge in the culture?

SEAN STRUB: Well, first of all, the two main incidents that I write about a little bit in the book were not with priests, but they were both people sort of fragrant with the Church, the essence of the Church. One was an usher at St. Mary's, and the other was a very senior official at school. And – you know, I mean, in terms of any insight: a few years ago, the *New York Times* did an analysis of all the cases that had been filed. And they counted them by year. And then they did them by geography. And the years with the greatest number of incidences that have subsequently been reported: 1972, '3, '4. That was the peak of when this was happening. And the geography of the country with the highest per capita incidence was the Upper Mississippi River. And I grew up in Iowa City; the high school was in Prairie du

Chien, Wisconsin. Our diocese, our Davenport diocese, was one of the very first to go bankrupt.

So I would guess, of the 68 students in my high school class – I'm sure a third of them were abused in some way.

SS: And why was it so prevalent? What's your take on it?

SEAN STRUB: I mean, I think some of this was this sort of clash going on with the Church, and you had all these – young priests kind of coming out of the **'**60s, and being caught up in gay liberation, and all that sort of excitement, and sexual liberation, at the same time. But they were in the priesthood. Those guys today aren't going into the priesthood quite as much. So that's where they were, and I think that the Church really sort of twists and perverts sexuality in ways that ends up being expressed in unhealthy ways.

SS: Okay.

SEAN STRUB: It was interesting. Years later, I wrote something in *POZ* about the abuse thing, because up until the time when I got very sick – I wasn't dismissive of people who said they had been abused; but I wasn't above making the joke, the crack, I wish I had been – you know, you hear people say that–

And then, at some time in the late '80s, I stopped saying, no, I was never abused, and I thought, because – it was like, I knew there was sort of like things that I kind of became aware that my memory wasn't there all the time. And then, when I was very sick and in bed so much, and watching things like Oprah, I became a cliche.

You know, suddenly, a big piece fell away. And oh my god, I'm remembering this, in very specific terms.

And then, I went back and talked to other people who in some cases I'd heard, in other cases I'd suspected, and corroborated all sorts of other kinds of details and things related to it.

So in terms of why then; why the Upper Midwest; I don't know.

SS: Okay.

SEAN STRUB: I really don't.

SS: So then you're in Washington, D.C. You've been a page in Iowa, and now you're in D.C. How did you –

SEAN STRUB: Excuse me; let me go back to one thing that may be helpful. So when I published the piece in *POZ*, and my dad read it. My mom reacted very poorly to it, and my mother was upset that I'd written about this. I'm not even sure she believed me. And my dad was upset and felt very badly. You know, this was a reflection on their parenting, and so on and so forth. But then he told me that when he was a boy at St. Mary's, that everybody knew to stay away from Monsignor [Carl] Meinberg; that he was the pastor at St. Mary's, and that he was a problem. But that he really only took advantage of the, the poor kids, the kids from broken homes; you know, the other side of the track kids. And I think that, and how that then reflected on him, and on us, that I was, I could get, like, sort of –

00:30:00

SS: Well, that they thought you were vulnerable.

SEAN STRUB: Yeah.

SS: So he felt implicated by that.

SEAN STRUB: Right.

SS: That's interesting.

SEAN STRUB: Oh.

SS: Oh, I think it's interesting that your parents read *POZ*. Did they read it from the beginning? Like would you discuss with them, oh, I'm starting this magazine, *POZ*, Mom and Dad, that's what I'm doing?

SEAN STRUB: Heh heh. I don't know how regularly they read it. But when it started getting press and attention and people saying nice things about it, they would hear that. I mean, a university town. And their friends were as much university-oriented as town-oriented. So they were in a milieu where lots of people admired it and spoke about it. And in 1988, my mother's best friend, who was a woman named Karlen, uh, whose brother, Burleigh Sutton, was one of the Dunesmen – you ever heard of the Dunesmen?

SS: No.

SEAN STRUB: The Dunesmen, someone should write a book about at some point. But they were Jim Hormel –

SS: Oh, huh.

SEAN STRUB: – Burleigh Sutton; Rob Eichberg; who's the guy, [Jerry] Berg – he was the first board chair at HRC. And I think – I don't have the whole story on it, but I think they sort of came out of an Esalen experience, in the '60s or early '70s. Which then David Goodstein, who owned the *Advocate*, turned into the

Advocate Experience, which it became the Experience Weekend, which Rob Eichberg ran up until he died. And it was sort of a self-actualization. But it really came out of Esalen. And I think the Dunesmen were a group of guys who went through this together, in a short period of time. And as it was explained to me, made a pact with each other, around gay political whatever kinds of stuff. And they were mostly from San Francisco, and there were 15 or 20 of them. Jerry Berg, was the guy. And they were – a really very big part of the energy that sort of drove the evolution from a sort of sexual liberation movement into a political reform movement – was happening in the late '70s and the early '80s.

But anyway. So my mom friend Karlen's brother, Burleigh, was very sick, with AIDS. And in 1988, in January, Tim Sweeney and Dan Johnston and I and a group of people went out to Iowa before the precinct caucuses to try and raise, you know, AIDS in the precinct caucuses, because the candidates were all over the state. And we did a series of press conferences around the state. And I got my mom and Karlen to host a fundraiser for AIDS Action Council, which was then the new Washington-based lobby that now is AIDS United, it sort of came into–, but was really formed by the big seven AIDS service organizations in the late '80s principally to lobby for funding for them.

And it was – I mean, I really admire my mom. I mean, as time passes, I realize kind of how really stepping out of her comfort zone it was, and – and they held it at the University of Iowa art museum. And of course, Mom and Karlen, I mean they didn't know anybody. They called everybody. I think she even got the pastor of St.

Mary's on the host committee for it, and a former governor, and just everybody they kind of like knew in Iowa to kind of do this big thing.

Two hundred people. And what I remember about – I don't remember how much it raised — ten or twelve thousand dollars — but it was a lot of money for AIDS Action Council at the time, in Iowa City, Iowa. But one of the things I remember most about the evening, because my partner, or former boyfriend of mine, had died like three days before, in New York. So I was –

SS: What was his name?

SEAN STRUB: Bobby Barrios. So I don't remember a lot of the evening. But I do remember they had a great big bowl of condoms. And my aunt,
00:35:00 Patricia Fitzgerald O'Brien, kept moving the bowl underneath the table. And my mother kept putting it back up, right? And Dan Johnston, who was a lawyer – Pope County, Des Moines County attorney, who then came out, and moved to New York — he's on the board of GMHC, and he's on the Civilian Complaint Review Board — then he moved back to Iowa, and he's the one I got to take on Nick Rhoades's case, when he went back to Iowa.

But Dan was there, because he was involved with AIDS Action Council. And he said something to my mother about how he admired how important she thought it was for the condoms to be out. And she said, she said, no, no, she says, I just wanted to see who took them!

SS: That's **funny. It**'s **interesting that you say that Jim Hormel; because he was a real contradiction. Because on one hand, he was putting all his**

money into gay rights; but his own company was involved in a huge strike, and he was a anti-union person.

SEAN STRUB: It wasn't a contradiction then.

SS: Explain, please.

SEAN STRUB: So when I came out in Washington, in Washington now, right, in 1976, spring of '76; and the first gay people I met, the first gay men I met; it wasn't Frank Kameny and activists out there — which there was a community, Mattachine Society, and there was that in Washington, very small and kind of centered around Lambda Rising, and the *Blade*. It wasn't that. It was very ultra-closeted guys in politics, from members of Congress to senior staffers to lobbyists to important journalists and pundits and so on. And there was no ideological distinction in the socializing. You would be somewhere, with people at totally opposite ends of the spectrum; people who were doing horrific things by day, homophobic things by day — let alone any other kind of issue — and no one thought twice about socializing with them. Because the oppression of the closet, to that milieu, was so all-defining that those political differences – gay wasn't about being –

The Human Rights Campaign Fund was being started by Steve Endean. It was right after Reagan had gotten elected. So Steve Endean — and stop me if I'm telling you history you already know — but Steve Endean was an Iowan – but who had been an organizer in Minneapolis. I think he worked for AFSCME. And was very involved in organizing gay stuff in Minnesota, and got the St. Paul nondiscrimination

ordinance passed, in ’74, ’5, ’6, somewhere in there. And then the next year, it was repealed.

But at this time, the Task Force was the only national organization of any stature. So the media, everybody, they were the spokespeople for the, you know, whatever it was –

SS: This is still the Bruce Voeller –

SEAN STRUB: Right.

SS: Right. Jean O’Leary –

SEAN STRUB: Bruce – well, Jean had just come in, after the truce was brokered around – you know, I’ve got all the Lesbian Feminist Liberation files downstairs. It’s another whole, you know, incredible story.

So Task Force was there. And then, it was starting to get – Goodstein, who was very important then, really wanted to focus on Congress. He wanted cosponsors on the gay rights bill, on the Abzug and Koch’s bill – it was introduced in ’74. And the Task Force was not equipped to deal with Congress. And they weren’t like operating at that level. And it was just more about media and doing some things with federal agencies.

And Lambda was then still mostly regional. Bill, Tom and –

SS: Abby Rubenfeld?

SEAN STRUB: This is before Abby, long before Abby. It’s very sweet, though; she just took on a criminalization case in Tennessee that I contacted her

about. No, this was – and this was when Lambda, I think, only had a half-time staff person.

SS: Oh, okay.

SEAN STRUB: When it had a shared desk at the New York CLU office on 43rd Street. But they were starting to become, they were raising money, and they were starting to go national. At that time, you had GLAD in Boston, you have NGRA in San Francisco; there's a little group in Los Angeles that didn't last long. But the gay legal stuff was basically regional, as all gay stuff was, at that point.

So Lambda was starting to go national. So Goodstein sets up Steve Endean to come to Washington and start Gay Rights National Lobby. And the deal was, kind of informally; the Task Force would do the executive branch; Lambda would
00:40:00 do the judicial branch; and GRNL – Gay Rights National Lobby – would do the legislative branch.

So Steve gets there. And the first thing he discovers is that the kind of retail politics that work going door to door in a neighborhood with city councilmen or whatever in St. Paul wasn't going to work in Washington. You had to have money.

And the Buckley v. Valeo decision, in 1976, that established PACs –

SS: Oh, okay.

SEAN STRUB: – had just happened. That was James Buckley, the independent senator, senator from New York State, William F. Buckley's brother; and Francis Valeo was the secretary of the U.S. Senate, and it really was around his

expenditures and his campaign. This is the precursor to Citizens United, that established PACs.

So Steve wanted to start a PAC, a political action committee, to give money to candidates. And the drama was what to call it, because it couldn't have anything gay in it. Not only would that limit who would give money to it — because the Task Force had their closet organization, called the Fund for Human Dignity. So at one time, most of the money was raised through the Fund for Human Dignity, and then it transferred to the Task Force. Which, back then, we didn't call the Task Force; we called it NGTF.

So he wanted to start a PAC. And my kind of political mentor, and guy I worked for and was very important to me then, was a guy from Sioux City, Iowa, named Alan Baron, who published a very influential political newsletter called the Baron Report. And Alan was also a genius at sort of positioning political appeals and offers. And so he was Norman Lear's guy when he started People for the American Way – take these issues and wrap them in the flag, and saying that the – what's his name – Wertheimer – in Common Cause. All those things that kind of came out of the post-Watergate – this was really actually kind of an exciting time in the country. There's a sense of national renewal. Reagan's – you know, you're just past the Vietnam War, just past Watergate. Jimmy Carter is running for president, saying, I will never lie to you. He had Congress, this whole group of Watergate babies, this freshman class in Congress, that were very reform-oriented.

And it was the bicentennial year. So Washington was all cleaned up and prettied up. The bicentennial logo was everywhere, and the country was proud and pounding its chest.

And so there was this whole group of new organizations. And direct mail as a fundraising mechanism had exploded. It had been around for awhile, but a number of different things, including advances in managing databases and postage rates and so on, suddenly made that the funding mechanism of choice for broad-based mass-market things.

SS: Richard Viguerie –

SEAN STRUB: Richard Viguerie on the left – on the right; Roger Craver on the right – or on the left. And so Alan did a lot of the work around Craver's clients, and writing and positioning things.

So Steve Endean – I had gotten to know him, I don't remember how I got to know him. And through me, he had gotten to know Alan Baron. And we'd hang out at Alan's townhouse, and talk about these things. And Alan was constantly poring over data. He'd love to find these kind of anomalies and things. He'd say, what religious group is the most reliably Democratic?

And he'd say –

SS: The Jews!

SEAN STRUB: Jews, right?

SS: Right.

SEAN STRUB: He'd say; he said, "if you took a certain sort of profession category of…" whatever it was – he said, "labor organizations would be the most reliably Democratic, right?"

And he'd say: "what are the great Democratic machines in the Northeast?" He said, "they'd be places like Erie County, Buffalo; Cuyahoga County, Cleveland; Allegheny County, Pittsburgh." And he said – and he says, "so tell me: who is a labor leader who's Jewish from Cuyahoga County?"

And you'd say, "Jackie Presser, president of the Teamsters."

"And he's for Nixon. So Alan would find, he's sort of, he'd find these patterns, he'd show how the voting patterns in Red Oak, Iowa, in the presidential races, were within a tenth of a point of the voting patterns in Long Beach, California, because of all the channelized migration that happened during the Dust Bowl eras, and it was basically 50 years later, they were voting exactly the same.

SS: Right.

SEAN STRUB: So Alan was like this really interesting guy.

So Steve was starting a PAC. And Alan was doing all this direct mail for these other social-change groups and political groups and PACs. And they were arguing over what to call it. Steve wanted to call it the Human Rights Campaign Fund;
00:45:00 and Alan said, Human Rights is an old phrase; we've entered a conservative era. That was one of his great things, is he's the one who called the Reagan election as a huge turning point for a generation, for the country, when others didn't see it. He said, it's associated with a failed presidency – you know, human rights was Jimmy Carter's

phrase. He's the one who really kind of introduced it in political terms, and used it for the first time since Eleanor Roosevelt. And he said, that's a loser. And he said, we need to frame this issue in terms that anyone could respond to. And he wanted to call it Privacy Project, you want to frame it on privacy, because privacy can be marketed as a conservative ideal as well. And I remember them going back and forth on this.

And so the first fundraising letter, which I have around here somewhere — the one that I got Tennessee Williams to sign — and I don't even think it mentions Human Rights Campaign Fund until about the third page; and it was raising money for Privacy Project '82, a project of the Human Rights Campaign Fund.

SS: Now this claim that you made earlier, that in this closeted Washington scene, people were socializing regardless of politics, does that include like Terry – you know who I'm talking about.

SEAN STRUB: Terry Dolan.

SS: Dolan.

SEAN STRUB: I didn't ever meet him or know him. But yes; that was within that realm. And it started to change after the election of Reagan. Because Reagan really introduced Jerry Falwell. In fact, it was actually a Falwell quote that we used at the beginning of the Tennessee Williams letter. So it was really the advent of the Moral Majority that was – Anita Bryant certainly kicked this off; but that was seen as localized and a person. The Moral Majority was sort of coalescing all these evangelical churches all across the country. And instead of homosexuality being seen as one of these list of biblical sins — fornicators, alcoholics, homosexuals, whatever;

just kind of over there generically, as these awful things — as a type of person who is a threat to you; not just a degenerate threat to themselves, but a threat to you and to your family. And that was a real transition that happened in kind of the public consciousness about homosexuality.

SS: Now do you think that was because they perceived this emerging gay movement as being left-wing?

SEAN STRUB: Well, I mean, to the extent that it was thought of in political ideological terms, sure. And that goes back long before then, to the Eisenhower-McCarthy purges and so on. But I don't think it was seen – I think it was more a moral-fiber kind of thing. It was more a response to the visibility and the marches and the parades and stuff after Stonewall, combined with the political opportunity.

SS: Okay, so let me just stop. So just as I asked you about the priests: looking back at these gay men, like Terry Dolan, who died of AIDS, et cetera, who were inside the Republican machine, and got Ronald Reagan elected; the precursors to the Log Cabin Republicans; how do you understand them?

SEAN STRUB: Well, okay. So – I'm not sure that they're the precursors to the Log Cabin Republicans.

SS: Okay.

SEAN STRUB: Because you had CAIR — Concerned Americans for Individual Rights — was a gay Republican group that came out of the Ford administration, that were quite moderate – these were not like anti-gay people. They

were not much of a force, but they existed. And I think there was a national gay Republican group before there was a national gay Democratic group. Tom Chorlton started the Stonewall Democrats, or what became the national, I guess it is still the national Stonewall Democrats. But that was just Tom Chorlton, and Chorlton recently died. And I don't think that even got started till like maybe '79 or '80. Maybe '78. Mel Boozer was nominated in '76; but I don't think there was any national gay Democratic organization then.

Because gay issues weren't seen in partisan terms, at least not in the world that I saw. It was sort of degrees of closet, and the gay politics was something totally separate. That was Frank Kameny, that was Barbara Giddings; that was the Task Force. And that didn't like really intersect with party –

You know, when Harvey Milk was killed, in Washington, the people that I knew – and by then, I knew a lot of gay people, my whole world was like – yeah, and I was getting interested in gay politics and gay activism, and reading the *Blade*, and so on. But it didn't – it's not that it didn't register, but he was, you know – the news coverage, the initial news coverage I remember reading, it was almost, it was like a
00:50:00 joke that he was gay. It was like an only-in-San-Francisco kind of thing. And in the political terms in Washington, that's a municipal-election, that's in San Francisco, had nothing to do with the political world –

SS: You know, the way I'm interpreting what you're saying, through my own lens, is that there was still a profound division between the

grassroots gay liberation, which was a left-wing movement, and gay rights, which hadn't fully emerged yet. You're talking about the emergence –

SEAN STRUB: Which was just starting, right.

SS: – of gay rights.

SEAN STRUB: Right, right.

SS: Right.

SEAN STRUB: Right, right.

SS: Which is completely divorced from that other –

SEAN STRUB: Totally.

SS: – yeah, trajectory.

SEAN STRUB: So Steve Endean was one of the first kind of bridge people. Steve, when he came to Washington – his sister published a memoir that he had been working on before he died. It's really, I think, really interesting at the time. Because he was one of the first people who came out of that real grassroots – Ethan Geto was another one.

SS: Uh huh.

SEAN STRUB: Who really consciously was starting to kind of, you know, or, in Ethan's case, came out of those – you know, he was Bob Abrams's guy in the Bronx, when Abrams was attorney general. So he came from sort of partisan politics. But most of these other people didn't.

SS: But he also had big-business connections, Ethan Geto.

SEAN STRUB: Subsequently. He didn't so much then, but yeah.

SS: Oh, okay.

SEAN STRUB: Now, he represents all these big bankers. But he ran the Dade County campaign against Anita Bryant, which was really the first national gay campaign that raised money nationally, in any significant way. Because Anita Bryant, everybody knew her. She was on TV, and the beauty queen, and Florida orange juice. And then saying these awful things –

SS: Save the Children.

SEAN STRUB: Well yeah, but it was – homosexuals can't reproduce, they have to recruit, and so on. And she took it on tour. You know, when she got in the face with the cream pie, that was in Des Moines.

SS: But she also really raised the whole gay-people-are-child-abusers thing.

SEAN STRUB: Absolutely.

SS: Yeah.

SEAN STRUB: Well, that had always been there. That was like in the thing. But again, it was sort of in this – the way I kind of saw it is kind of, you know, I call them the sort of generic list of biblical sins sort of out there, that people didn't really talk about. It was kind of like there. But this made it about an individual who is a threat. It was about looking around. Who's your neighbor, who's at the school? And then Jerry Falwell even more so, who really made it political, even more political.

I don't think Anita Bryant was intending to make it political. I think she just thought this ordinance was terrible, and she wanted to overturn it, and did so –

at some sacrifice to herself, actually. I think she's still alive. I'm waiting for somebody who's –

SS: Yeah, we were just talking about that today.

SEAN STRUB: – clever enough to have a relationship with her, and you know – maybe she's got a –

SS: Revisit.

SEAN STRUB: – you know, a queer grandkid or something, who will give her a drink or two, and get her talking some day, because that'd be fascinating.

SS: Don't you have – so then you have Reagan elected, and you have the huge triumph of direct mail, which many people thought was the background of that.

SEAN STRUB: Yeah.

SS: Of his victory. Yeah.

SEAN STRUB: It was a very big part of that. So right after Reagan got elected, there was a party that Adam Nagourney and Dudley [Clendinen] write about in *Out for Good*, that Alan Baron hosted, that was this huge party during the inaugural festivities. And you know – it had Barney Frank and Peter Kostmayer, and you know – the Democrats. And it had – I can't think of any individual names. I don't think Terry Dolan would have been there, but he could have been, I don't know. But it had the whole mix of everybody there. And it wasn't long after that that I think the social circles started to polarize.

And some of this was driven just by younger — and I'm talking almost entirely about men here — younger gay men who were not happy with that kind of hypocrisy. Maybe they didn't articulate it, but they didn't see that; but I remember not understanding why the McDonald amendment would fail on a voice vote. But then, when it went to a recorded vote in committee, we didn't get a single vote on it.

SS: What was the McDonald amendment?

SEAN STRUB: Larry McDonald was a member of Congress, a John Bircher, from Georgia, who proposed legislation to prohibit any federal legal services money from being used on anything gay. And that was – Dan Bradley was the first federal appointee who was openly gay, when Jimmy Carter made him head of federal legal services. And so, oh, he's then going to turn it into campaigning for the homos. And so – and I remember Steve Endean explaining that. I forget who was on the committee at the time, but there were people who were our friends, and they didn't even have the guts then to, you know.

And the whole thing around the name, by the way, was not only did the
00:55:00 name have to be a closet name for people to give money to it, it had to be a closet name for members of Congress to accept the check from it. They wouldn't accept the check if it was something explicitly gay.

SS: So then you have 1981, and AIDS begins. And when did it start to get on your radar?

SEAN STRUB: Right. Yeah. And AIDS begins is – that's when the CDC recognized the first cases, and so on. But for most of the gay community, it didn't begin then. They had no idea. There were about – a very small number.

SS: What about you?

SEAN STRUB: Well, for me, I was a volunteer copy editor at *the Native*. And so I remember when –

SS: The *Native*, in New York.

SEAN STRUB: Yeah, the *Native* in New York.

SS: Now wait; how did you get from all this freewheeling in Washington, D.C.,

SEAN STRUB: Okay –

SS: – to the *New York Native*?

SEAN STRUB: What happened after –

SS: Okay!

SEAN STRUB: – after Harvey – so the, I came out to my parents in the summer of '78. Just sort of a timeline: in the summer of '76, I was in New York for the convention. And I'd never went to a gay bar, anything like that. I remember going by a room — there was a little meeting that there was going to be, a little gay-caucus thing there — and I remember going by, and kind of looking. You know, there were like five or six people there, and I didn't go in. So at that point, I was still too afraid in that thing – but I was on a political track. I had a – by then, I now had a career – I want to be in politics, so.

And then, over the next two years, my circle expanded, and I came out much more. And then, when Harvey Milk was killed — not directly because of that, but in the month or two after that — I decided to move to New York. I had been hitchhiking from Washington to New York on weekends. I'd started to really like New York, and I was making friends in New York. And very different friends from the sort of closeted circle in Washington. I never broke into a gay activist circle in Washington while I was there. It was just a bigger and bigger circle of people on the Hill, and people – very powerful people, in many cases, but very deeply closeted. And New York was more exciting to me. And I'd started to become sort of outspoken enough about gay stuff that I knew I was being shunned by some people. I saw doors closing to me in Washington, in a very subtle way, even amongst peers my own age. I was like suspect, if you were around. So I was spending more time in New York. And then, after Harvey Milk was killed, I decided to move to New York. And I did.

And started summer school at Columbia in summer of 1979, and moved in March of '79.

And then, that fall, I went back to Washington for the March on Washington. And Ethan and Doug Ireland were staying at Alan Baron's house, because they were friends of his. And – I forget how they knew each other, but I think Stewart Mott might have been involved. But at any rate – so I spent the weekend with Doug and Ethan, who then were very-best friends. They ended up not being such good friends. And I had gotten a job working for the New York State Assembly's office in Washington.

No, that was earlier. I'd moved to New York, I no longer had that job.

But I remember Ethan and I were going from the back of the march to the front, and we were kind of jogging. Of course, Ethan is so huge. And it was fascinating, going by, and seeing people with the banner from Kansas City, and this was the first march of this – all kind of amazing. And I remember, when we went by the New York State delegation, Ethan yelled out: "Where's Joe Crangle?" And Joe Crangle was, for years, the New York State Democratic chair. And for many years — decades, I think — he was the Erie County chair. He ran the Erie County machine. Ran for national chairman at one point. And, closeted gay guy. And he's the one who had hired me for this job. It was basically a patronage job, and I slept with him, which I write about in the book.

And we're going by, and we're kind of jogging by. And Ethan yells out, "Where is Joe Crangle?" And I just couldn't believe he said this. And everybody cracked up. They all are, because everybody knew, because –.

I go back home, to New York. I write this long letter to my parents, like four or five or six pages, explaining, very grandly, how I was devoting my life to the gay rights movement, and predicting all sorts of things I thought I would see in the future. And then at that point, I didn't care who knew I was gay.

I was still taking jobs where I was like closeted within the job, but I
01:00:00 was willing to zzdeal with the risk. I wasn't lying or anything; I was keeping my private life private, kind of thing.

So then, by early 1981, I was executive director of the Kentucky Democratic State Committee. But I was flying back to New York on weekends. And my apartment was on 58th and Ninth, and the *Native*'s office was on 57th Street and Eighth. And so when I say I was a volunteer copy editor, maybe six or eight times I was over there. I think I was hanging out with Brendan Lemon one time, and Tom Steele. And it was just like –

SS: Dee Sushi was Tom Steele, right?

SEAN STRUB: Dee Sushi, yeah. And I don't know if you knew Brendan Lemon or not.

SS: No.

SEAN STRUB: Okay. Because he had moved, he had graduated from Iowa and moved to New York, and lived with me for a while. And he got all involved with the *Native*.

Anyway – so I remember – and I was getting a copy of the *Native* at my P.O. box in Kentucky. So I remember reading Larry's first article. But that was an article – it was just like this sort of peculiar thing happening. It wasn't anything that gave you any reason – gave me any reason to be afraid or concerned, or whatever like that. It was just this weird thing. You know, guys were getting ill – were gay, and all had this strange gay cancer.

And then, but when the *Times* article came out, in July – I was actually, on June 5th and 6th, when the CDC considered the date and start is when – that's when the CDC first published something about it in the *Mortality and Morbidity Weekly*

Report — not like I read it; I mean, I don't know anybody who read it — but I was with Vito, in Denver, that very day, actually. And when Michael Shiavo wrote that book, he had these things about Vito saying that night that Vito and I were snuggling in bed, and after this incredible day, and that I told Vito, if I were to die young, I wanted it be after a day just like this. I'm reading this, and saying, this kind of sounds familiar, but did I tell him that? I wasn't, like, sure. Maybe I was getting like really grand in my recollection, and I thought – He said, "no, it was in Vito's journal." He got all this stuff from Vito's journal, about meeting me there and writing about it. But that was actually, that was that day.

SS: Now why were you both in Denver?

SEAN STRUB: I was there at a Democratic National Committee training academy, and was staying with Adam Reilly and Ev Engstrom, who I knew from Washington. Adam was the head of the Denver Center Cinema. He had been at AFI in Washington. And Ev was then in law school. Adam's gone, and Ev is now in the D.A.'s office in Denver. And Adam was a big film guy. And he had invited Vito out to do the presentation of *The Celluloid Closet* at the Denver Center Cinema. So Vito was there. But I'd met Vito in January of that year at the Roosevelt Hotel, at a gay press association thing, and kind of tried to pick him up. And he was also, he worked at the snack counter at the St. Marks Baths. And the snack counter at the St. Marks Baths, you could actually go to without going in the bathhouse. There was a little part of it in the waiting area. And I sometimes would go down there and do my homework, and he would give me free carrot cake, and tell me about the days of the Firehouse.

But when the story in the *Times* came out, that identified the three symptoms that a number of people shared; I remember really kind of – feeling, you know, getting a queasy feeling, because they all hit close to home. The symptoms were persistent swelling of the lymph glands, the weight loss, and the night sweats. And in the fall of 1980, I was at Sloan-Kettering, because they thought I might have some sort of weird lymphoma. Columbia University health service, student health service, had sent me there, because they didn't know what was wrong with me.

And I had lost about 10 pounds after I moved to New York. Which, at that time, my weight fluctuated. I didn't pay any attention to my weight. I didn't have a scale. But when I read that, I real-, yeah, I am skinnier than I used to be. And I just always thought I sweat a lot.

But I remember reading that. And so from then, I was really paying close attention. And early in 1982 – I was walking along Seventh Avenue, at Christopher Street. And there were guys there, at a table, for GHMC. And I was like,

01:05:00 sort of standing there, reading the literature, but afraid to pick it up and take it with me, but standing there, reading it. And of course, a couple of the guys were very cute. And one of them said he had to go somewhere, and said, here, would you do this for a while? And he gave me the can, just like that. Okay, quaking and shaking.

And I remember somebody I knew walked by, and he sort of looked at me, and was like, what are YOU doing shaking that can?

And in Kentucky, I was living with John and Helen Thompson, who I knew from Iowa City. He was a doctor, and he was the head of the – the chairman of

the Department of Medicine at the University of Kentucky. And I was out to them. And I started showing him the articles in the *Native*, through late 1981, before I moved back to New York. And he was fascinated and had all sorts of ideas. I actually have a letter from him, where he wrote, saying he thinks it's probably a virus. And all of a sudden, he later wrote me a note, saying that they got involved in research at UK probably a year or two years earlier than they would have, simply because of giving them the *Native*. And after I came back, in fact, the *Native* was still going to my P.O. box, which they would pick up, which he would open and read. Which was –

SS: So he learned about swine flu and airborne monkey –

SEAN STRUB: This is, no, this is before swine flu.

SS: – this is before all of that.

SEAN STRUB: – this is before swine flu, yeah.

SS: Okay, yeah.

SEAN STRUB: At that time – I remember when Way Bandy died; and Joe McDonald – Joe MacDonald was a big effect on me, because a friend, roommate of mine had been kind of dating him some, and Vito and I had had sex sometimes, so it was like the first time I, like, sort of, you know, did the Venn diagram in my head, and saw myself in it. And that was early in '83. And here, you know, sort of a step removed a little bit. And then, in fall of '83, I think Jason Muller died, who was my friend Nick Lattimer's partner. And I remember Nick telling me; you know, Jason was sick; but not using the word "AIDS." And he's like describing this. And I finally said

to Nick, I said, it sounds like he has AIDS. And I've never known, to this day, if that was the first time it had crossed Nick's mind or not.

SS: Wow.

SEAN STRUB: But that was very kind of traumatic. And Jason also was from Iowa. And then, in '84, two very close friends died, two people I had dated and was very fond of and was still in touch with.

SS: And who were they?

SEAN STRUB: One was Jim Nall, who was sort of the first friend I made in New York. And he was an intern, he was a neurologist, at Mount Sinai. And he took me to the ballet for the first time, to the opera, and was sort of that kind of cultural mentor, and was just so much fun. And he had moved to Texas. And we had stayed in very close touch, and I'd visit him occasionally. And when I bought a house in Bucks County, in '83, he loaned me two thousand dollars towards the down payment. And he wanted me to come to see him, in Texas. And I knew he had been ill, but not, it wasn't anything.

There were so many people who were a little bit ill, and you didn't connect it. At that time, I remember talking to a doctor about my swollen lymph glands and everything, and him telling me that that meant I didn't have AIDS. Because at that time, people who had AIDS were very, very sick and were dying. And because my lymph glands were swelling, it meant I had an immune system; it meant I was still responding to it.

SS: So you were symptomatic for four years before you got –

SEAN STRUB: Before –

SS: Because you said when you first saw the *Times* thing, you were already symptomatic. And now, in 1984 –

SEAN STRUB: Oh yeah, yeah. I also had a really awful flu, in 1979. But I don't have the medical records on that. But I do on late in the fall of 1980. So one of those was my seroconversion sickness. And the person I was dating through that period is the other person I'll tell you about who died in 1984.

01:10:00 So Jim then really wanted me to come see him in Texas. And he had frequent flyer miles. And I flew down there to see him. And – and at the airport, he had a baseball cap on, and his face was covered in KS, and – and that was just, you know, very intense, and stayed with him for a couple of days. And he died about a month later.

And the other person who died that year was Robert Hayes. So Jim and I had had sex a few times, but then we were just really good friends, and I used to stay at his apartment when he was in New York before he moved to Texas.

But Robert and I met on his birthday, August 4th or 5th, 1979; and dated for about a year. And Robert worked for Warhol. He was managing editor of *Interview*. And in the spring of '84, we had lunch, and he was showing me – they had just moved to the new Factory, on 33rd Street. And he was going to show me the Factory, and we were going to have lunch. And we got there, and he started going up these stairs, and I could tell it was a strain for him. And I said, let's just go to lunch.

And we went to lunch, and we mostly talked about his boyfriend Cisco, who was very sick — with AIDS — we knew Cisco had AIDS. And Robert was like coughing and wheezing. And Paul Rapoport had just shown me how – a sort of test for PCP – take a really, really, really, really deep breath, and if you feel a pain in the middle of your chest, you need to see a doctor. So I remember showing that to Robert, and him taking a deep breath, and claiming he didn't feel any pain, or whatever. That was in May.

And I remember leaving him on the sidewalk, wondering if that was the last time I would see him. And a few weeks later, he was in the hospital, at Lenox Hill. And I talked to him a couple times. He didn't want anybody to visit him. And he died in July.

So those are two people who were very important in my life, who died in a very short period of time. And that was sort of from that point, everything was different for me.

SS: So how long were you symptomatic before you were diagnosed?

SEAN STRUB: I didn't, I mean, I was diagnosed not long after the test came out, in '85. So –

SS: Five years.

SEAN STRUB: Uh, yeah. And the only reason I got tested then was I had shingles really bad. That I actually thought was the world's worst case of poison ivy. And went to see a friend – I didn't have a doctor in New York at that time, so I went to see Nathaniel Pier. Who was my friend Max's – Nathaniel was a friend of

Max's, and his doctor. And he immediately diagnosed it as shingles. And told me – I remember – I didn't have tears in my eyes until he had tears in his eyes when he was telling me this, you know. Because on one level, I was like prepared for it. I was one of those people saying, oh, I probably have it, I probably have it. But the test was relatively new, but the – but it was still, of course, shocking.

But he held both my hands across his table, like this. And he looked at me, and in all sincerity, he said: Look, Sean; these days, you can have two good years left. So that was in the fall of '85.

SS: Now how do you understand your own epidemiology? Do you feel that maybe you had a weak strain, or how do you see that you were able to go so long without getting really, really seriously sick?

SEAN STRUB: Well for one, I guess maybe I don't see that as unusual as your question, your tone, implies.

SS: Okay.

SEAN STRUB: Do you think it is? I think a lot of people, like me –

SS: Um hm.

SEAN STRUB: Having said that, I also know that I do have one of the deletions; the pair of genetic deletions, that are associated with slower progression. So I do have that. But I know people who don't have that, who also have been very slow to progress. And –

SS: Because you're telling me something that I don't know at all. So you're saying that there is a gene test –

SEAN STRUB: There are two, yeah –

SS: There's **a link –**

SEAN STRUB: – there's a genetic test. There are two mutations. And if you have both of them, I don't think they say it definitively. But pretty much, you
01:15:00 can't get HIV. And about one percent of Caucasian men in the U.S. have both deletions. If you have one deletion, it's associated with slower progression. And about eight percent of Caucasian men in the U.S. have that one deletion.

SS: And how accessible is that test?

SEAN STRUB: Well this is very interesting. Because of course, this goes to issues about treating immediately, and all sorts of things like this, that I'm always talking about. The test – it used to be it was just a lab in Atlanta. So you had to get a doctor who would draw the blood, and then overnight it to this lab in Atlanta, that charged 300 bucks for it. But now, the 23andME test — these sort of genetic things — it's one of the panels on it, right there. So for 99 bucks, you get your whole thing, and it'll tell you if you have that as well.

SS: But shouldn't everyone –

SEAN STRUB: Thank you. Thank you.

SS: Because I don't even know about it. I mean, I don't think it's commonly known. It should be a factor in treatment decisions.

SEAN STRUB: Thank you. And it's probably not the only – I think there are some other genetic things that have been found as well. There are different theories about this. For a long time, the belief was that this was a mutation that

developed out of the plague years. And they used to say that the more Northern European blood someone had, the more likely they were to have these deletions.

Now, Bob Rohrer has sent me an article on something that shows a different correlation with it – around the Baltic states, or something like that. But I think they've now found other genetic anomalies that are associated with degrees of progression.

But beyond that, I think I brought a lot of skepticism to the healthcare system. I didn't interact much with it as a patient, as a kid, or anything like that. I had broken limbs, and things like that. But I grew up in a county that I think had about as high a per-capita number of MDs of any county in the country. I think only Fairfield County, Connecticut, had a higher per-capita of MDs, because of this big university hospital in this relatively sparsely populated Iowa county. One out of 70 people in the county was an MD. We lived right next to the hospital. At least half the people on my paper route were associated with the hospital in one way or another.

The only time my mother ever had a job was in the early '70s, when lots of her friends were going back to school or getting jobs – it was kind of a thing for them to do. She got a job with our neighbor, a lady, Janice Hynes — they got jobs as programmed patients at the med school. Where they would be given a set of symptoms, and the med students thought it was just a public clinic. They didn't know that there were these women, incognito, who were evaluating them or giving these – And then my mom and Jan started rating them on other things. Were their fingernails clean? Did they look them in the eye when they said hello? Did they introduce

themselves by name? All these other kinds of factors that were important to them, right?

SS: Right.

SEAN STRUB: And I just grew up with a sort of suspicion of the idea of the guy in the white coat is some sort of god. I used to say that on my paper route, the doctors were the worst at paying their bills.

So I came to this with some measure of – sort of suspicion about health care and seeing health care in political terms. Because abortion rights battles in the early '70s, and the Equal Rights Amendment — all that stuff — that was what framed my political consciousness. Those were the first campaigns I was involved in; that was where I, as a kid, was welcomed – as opposed to other backroom party politics. So from the beginning – and I guess I just knew – when I met Michael Callen and Michael Hirsch, they knew more about this than any expert I was reading about anywhere. It was just so obvious to me.

When Nathaniel Pier — and sometime a few months after I was diagnosed, he was very excited. And he was able to get me access to AZT. Which any doctor who knew about it could actually get access at that time; only a very few probably knew about it.

And so at first, I'm like, I'm kind of like flattered; you're getting, like, the secret, inside, you know, whatever whatever. And of course I said yes. And Michael Callen, you know, was Michael Callen with it. And so I would like, listen to that. And – And I took it for about a month or six weeks, and I can't say that I

necessarily bought into Michael Callen's trashing of it, or that it was, you know, the side effects were so awful. I'm not even sure why I stopped. I think it was just

01:20:00 something that on some level, made me feel sicker taking it than not taking it. And I'd be dead, if I had continued to take it, you know. This is –

SS: Can you just explain really clearly why you would be dead if you had continued to take it? Just for the record.

SEAN STRUB: Because the – because it accelerated the development of resistant strains of the virus – AZT monotherapy. And so for people who were on their deathbed, who were very, very, very sick, it was a miracle. I know people, I know somebody, who was literally – we didn't think they were ever going to get out of hospice care. And they started on this, and they were up and about, and going to dinner, in a few weeks. So people saw this miraculous response for people who were very, very, very sick. And it lasted a few weeks, or a few months; and then the virus got around, and came roaring back, and killed them.

So that experience was then – Burroughs Wellcome really tried to extrapolate that to everybody who was testing positive, which was a vastly greater market. And there wasn't a real reason to think that that would work that way; but that it would achieve the unfortunate result of creating resistant virus – as well as the accumulated toxicities. Because at the time, you were taking so much of it. I mean – at the time, whatever side effects they felt tolerable to me; now, when I look back; how could you take twenty-four-hundred milligrams of AZT? Even when it was later used

in Combivir — it's still used in some things — it's a fraction of that amount. You know, the getting up in the middle of the night, and it was just –

SS: Now what were you doing for a living at this point?

SEAN STRUB: So in the early '80s, I was running these party organizations. I was later executive director of the Pennsylvania Democratic Committee, state committee, then I ran a congressional campaign in Florida. And between those kind of gigs, and campaigns, and party organizations, I started writing fundraising copy. Tim Dlugos was the first person to ever pay me to write something.

SS: Tim Dlugos, the writer?

SEAN STRUB: Yeah.

SS: Oh, wow.

SEAN STRUB: Yeah. Because he was a creative director at a fundraising firm.

SS: Oh, I didn't know that.

SEAN STRUB: Sanker, Berlin, that's how he earned a living.

SS: Oh, okay.

SEAN STRUB: And in some ways, he had some kind, he used to live in Washington, and he was a political junkie, and he was a former Franciscan seminarian. So I started writing fundraising copy, in between those other gigs. And then it turned into a business. Todd Collins was my business partner. He was the chief of staff for Penn and Schoen — Mark Penn and Doug Schoen's survey research firm, in New York. Mark Penn later became Clinton's pollster. He's now the, I think,

worldwide whatever at Burson-Marsteller. And Todd and I started a firm. So this is in 1985, we started the company; '85 or '84 – '84, I think. And our business plan was we were going to focus on three areas, because what was happening in the direct-mail fundraising industry at the time is that there was more and more specialization. So there was the Richard Viguerie on the right, and Roger Craver on the left; but then it was specializing further, and there were people who did, you know, health appeals or environmental appeals.

And so we identified three niches that we thought we would specialize in. And one was in homelessness and urban problems. And another was environmental work. And the third was gay and lesbian stuff, because I was doing volunteer fundraising stuff by that point, for SAGE and some other groups.

SS: Now in that era, 1985, what would be the percentage that a company would make from something like that?

SEAN STRUB: The percentage a company would make on what?

SS: Like how do you earn money doing that?

SEAN STRUB: Well, there were different ways. So there were, what we always resisted, and wouldn't do, were percentage fundraising things.

SS: Oh, okay.

SEAN STRUB: There are some companies that will do X for a percentage. The way we did it; two different ways. What we liked to do is to develop a client that would pay a monthly retainer, that would be two to four thousand dollars. And for that, we would produce X number of appeals per year, and we would produce

X number of pieces of prospecting mail, and we would bid it, and they would pay the bills directly to the vendors. And we were just paid a coordinating fee.

Sometimes, depending if there'd been an extra creative fee. There were
01:25:00 little bells and whistles that we would have on it. But a lot of the work that we did were sort of one-time projects, where we would provide a quote for the whole project. And so depending on what we did in-house, right; if we did the copy in-house, obviously we were making that. As I created my own database, and we'd rent those names back to our clients, which was a real key part of it, was the database that we created in-house; we'd make money on the list rentals. A lot of the contracts called for an agency markup on third-party contracted things. So the printing; we would go out, and we would get the three quotes. The client would select who they want to; and we'd get 15 percent, or I think sometimes it was 17 and a half percent, on top of that, like an agency would for placement. The postage; you couldn't mark up of course.

So there were different scenarios.

SS: This is a really naive question. But did they pay you after they got the money from the fundraising, or did they have to pay you before they got it?

SEAN STRUB: It depended on the client.

SS: Okay.

SEAN STRUB: Most clients, we required that they pay us before. Some clients – if it was work we really wanted to do – see, because what we were

generally interested in were groups that were scratch starts, that were not established organizations, right?

So if the Federation of Protestant Welfare Organizations hired us — right — this was the fee; whatever the mailing did, tough luck; that's whatever it is, right? But when we would do something for a grassroots group that we were interested, that we wanted to do it, that we felt would work in the mail; they typically didn't have any capital, they didn't have any ability, it didn't matter how good the offer was, they didn't have any ability to finance it. And often didn't have much understanding of the process. So that became a huge part of explaining how this works.

Ken Dawson was really a critical part of that.

SS: Oh.

SEAN STRUB: Because SAGE was my first, you know, paid client. Because I'd been doing their mail on a volunteer basis for several years. It was enormously successful. And Ken kept wanting us to do more and more and more and more. And – wanted me to do more and more.

And there was a congressional race that was going to hire me, and I wasn't going to be doing anything, and he said, what are they paying you? And I told him. And he said, well, I can't pay that much, but I'll pay you a thousand dollars a month if you'll run our mail program.

So what would happen would be something like – we'd do a test mailing, that typically would be 50,000 pieces of mail. And it would typically be 10 to 15 different lists. And each list would be three to five thousand names. So if – the

ACLU list was whatever; half a million names nationwide. You wouldn't mail 50,000 names to it; you'd mail 5,000 names throughout the whole thing, to see if it works, right? And if the 5,000 worked, and you met your needed level of response, then you'd go back, and you'd maybe take 25,000, and work it up to –

And so the idea was how to get – and this is in the acquisition mail. It's called prospecting mail, or cold mail. That you're sending to people who have never given the group money before. Right?

SS: So you would send a fundraising letter for SAGE to the ACLU list.

SEAN STRUB: Right.

SS: Okay.

SEAN STRUB: Right. And I don't know if we did that specifically, but that's the –

SS: An example.

SEAN STRUB: So – this is different from the resolicitations, right? So SAGE, we would say, we would, like, get the Gray Panthers list, right? Or we'd get other lists that would be sort of intersecting issues. And we would then go out, and we'd mail 50,000 pieces to, say, make it easy, 10 different lists of 5,000 each. Well, one of those lists returned the best, and one of them was the worst, right? And usually somewhere in the middle, below this level, we didn't want, you know, it was too poor a response, it wasn't worthwhile. But above this, we'd go back and mail to more of those names.

And so then some of our contracts got to — and this is where in some cases it became very profitable for us — that we would be paid 25 dollars per thousand pieces mailed, within their parameters. So that if the response was above X point – so as big a universe as we could find, that that would work for; and that became significant, if you're mailing hundreds of thousands of pieces of mail, and you could find a universe where that would work.

SS: Now were you the only people doing this? Or was there competition?

SEAN STRUB: Oh, there was a lot of comp-, well, in, in –

SS: Yeah, within the gay world.

SEAN STRUB: – in the gay – there was – there was some competition in the gay world, but mostly people who used to work with us, that went off, went on their own, or they developed a relationship with a client, and then the client hired them directly.

SS: But you innovated this, for the gay community.

01:30:00 SEAN STRUB: Around the gay stuff, yeah.

SS: Yeah. Okay.

SEAN STRUB: Tim had started doing some mail for the Task Force in, I think even maybe like '78 or '79. But the board didn't understand it, and they let it drop. I mean, they did a mailing, and it lost some money, and they freaked out.

When – I don't know what the economics are today. But back then, if somebody gave 35 dollars to the ACLU, for the first time, to join the ACLU; or NOW,

or NARAL, or whatever, all the groups that mailed – Planned Parenthood, whatever; typically, that organization might have been spending 60, 70, 80 dollars to get you to take that action, to send them 35 dollars. So they would have a net investment – they paid 50 bucks to get you to give them 35 dollars, right? They'd have that net investment.

Because they know that once you've given to them once, a significant percentage of you will then give to them again, and it becomes profitable over time.

And the problem of a lot of organizations is, they want to look at it as a mailing. And it's not. It's a program. You have to look at it over a year, or two years, or three years. Because direct-response fundraising, looked at in a very narrow window, is generally a very expensive kind of fundraising. Because it has a huge capital cost upfront, to create the donor base. But when you look at it over time, it becomes much more competitive, cost-wise, than events or other kinds of fundraising things.

And so getting groups to sort of think in terms of a three- to five-year window of building a program over time was one of the challenges.

But, then, what we found — and this – I saw your interview with Peter Staley, with ACT UP — to why we could do it so profitably for ACT UP — was that with the groups when we provided the financing — so sometimes, we would put up the money for them, sometimes even for the postage. And sometimes we would guarantee the result. We would say, usually guarantee that you will not lose money on this, right?

So you're going to a group, and you're saying, we're going to send your letters to all these people who have never given you money before; and there's no way you're going to lose money. You know. At the very worst-case scenario, you're going to have a bunch of new donors – and no cash. But you haven't risked any cash.

So that's a pretty irresistible offer, right? This is something no one in the direct-mail business did, because there was always risk. You send out mail, and it gets delivered on the day the president gets shot, or there's a hurricane or something; nobody's reading your direct mail; they're all watching TV. It's sensitive to all sorts of different kinds of things.

But, there were times when – well, first of all, we were putting together lists of our own. So whenever a gay publication was going out of business, or all that group of gay catalogs that started, or travel agencies; I'd be at the bankruptcy sale, buying the database – or just doing deals. Steve Cohen, the party promoter – whatever, you know. So we were creating a big of a list as we could internally. Because what happened was — and this started with SAGE, when they created a great fundraising letter for SAGE, from, Bruce Merrill and Jean Harwood signed it. It was a really wonderful letter. And we exhausted – there were about 60,000 gay names that could be found, and we exhausted them. You mail them. And actually, some of them responded so well, we could mail the same letter back in the exact same list a month later, and it still was profitable, you still would get enough coming in. People would freak out; they're getting repeated appeals. But it was still, economically, it made sense for the group.

But it was a small universe. There were 60-, 70-thousand names were all that were available at that time.

So we went out, and first started buying and acquiring any kind of gay list, whether we knew it was direct-mail responsive or not. It could have been petition-signers. The Islanders Club, Blue Flettrich. You remember Blue Flettrich. Islanders Club was a bus service out to Fire Island. Anywhere we could get, to put together this database.

And then – I created overlays onto other lists. So like the ACLU list – if you just went to the ACLU list, it wouldn't work; it was too broad and generic. But if I took just men on the ACLU list in zip code 10014 — right? — that might work, right? And you'd do all these sort of things, in a million different ways.

I had a list one time that was just marginal. If I could just bring it up the slightest little bit, it would have been worth going to, and it was a big list, so it was worth the effort. And so I went back and did another test on it, but I only took the addresses where the house number ended in a zero or a one. Those are corner houses. They're more affluent, on average, than the other houses, and affluence will bring a response up.

01:35:00

So you could do all these little things to create these overlays.

We would send out a list – if you've ever bought a toaster or a hair dryer and it has a warranty card, and it asks you all your hobbies, right? Do you enjoy hunting? Bible study, whatever? That was a big company, called Lifestyle Select, in

Denver. And they put together a database of about 90 million records. And they had all this information people volunteered about their hobbies and their interests and so on.

And so I would hire them to create a model off of my names. So I would take them – I would, say, have 7,000 names, a database, at that time. I would send those to them. They would match that against their 90-million file. And maybe fifteen hundred of those 7,000 names would be on their 90-million file, right? But now they have fifteen hundred that they have all this demographic data on. And they'd say, oh, foreign travel; oh, gourmet cooking; oh, going to the theater; you know; whatever it is. And hunting and Bible devotional study is way down, right?

So they could then go back into their file, and identify other records they have that scored in a similar way. You create a model. And then they would come back, and they'd say, well, we have these 400,000 names. And they'd break it into demi-deciles. And I'd start at the very top, whatever the demi-decile would be — 20,000 names — and would test that, and see if that would work for the given offer. If that worked, I'd go to the next one, and you'd go further and further away.

So we created all these different ways to identify potential donors for these organizations.

And some of this started, literally — because this was really an early era of technology — I remember I had a list of like, it was less than 2,000 names. And I had the computer place — and this is on green-and-white-stripe paper — I said, sort them by zip code. I wanted a count of how many were in each zip code. They couldn't do that. I said, sort them by zip code. Not even the carrier route, not even the nine-

digit zip code, just the rough zip code. And then I went through, and counted. And these were all in New York. And I went through and counted how many in 10014, how many in 10011; 2, 3, 1. And then I looked up the population in each zip code, and calculated a penetration value, right, for a zip code. So, and found out these were the gayest zip codes, from this file. So then, when I was going to another list, I would then prioritize those zip codes. And eventually, we ended up doing this all over the country and creating voter files in California, and so on.

SS: So how did you come to do this for ACT UP?

SEAN STRUB: I have to tell you one quick anecdote about California – the MECLA [Municipal Elections Committee of Los Angeles] list, when – MECLA list, the first municipal gay PAC – Mixner and a bunch of people were involved in. And through Jean O'Leary I was getting to all these people, and telling them all the stuff we were doing with the database.

And they said, could you identify gay voters on the Los Angeles County voter file?

And we did come up with a way to do it. And we ended up – then we went back and checked it, we did a phone survey where we would call and ask opinions about AIDS issues. You couldn't ask people if they were gay. But you'd say, do you think AIDS is a serious problem, whatever. These other things that you came up with, these markers for it. And it worked pretty well, except that we ended up identifying an awful lot of unmarried men living together who we thought were gay, and they were nursing homes, but that's another story.

SS: Oh, okay, okay.

SEAN STRUB: And then there's also the story about the time the Shocking Gray catalog was sold to a guy named Rick Hutcheson, who I think is on the Palm Springs City Council, or something. And we kind of, we ended up not working with him. And he didn't really understand how to order lists, because it's a whole industry of lists; thousands of different lists available. And when you're ordering lists, there's something you can do called a slug, that you can put in – when you get something that says, "To the homeowner at," right? Or "to the parents of" – whatever. It's just like a title, put in on the label.

And he somehow miscommunicated with the list broker he was using for this. Because he was looking for women, he was looking for lesbians. And he ordered this list; and had the list sent on labels directly to the mail shop to send out his catalogs. And he sent all of his catalogs that said, "To the lesbian at" 123 Main Street.

SS: Oh my god.

SEAN STRUB: Ah! We had lots of those stories.

SS: Very funny.

01:40:00 SEAN STRUB: Liz Holtzman, when she was running for the Senate, I was doing a fundraising thing. They wanted me to write it, and create it. And then they didn't want us to handle the printing of it, because they thought they could get that done cheaper. Fine. So we sent them all the mechanicals for it.

Well, they hadn't provided a return address for the return-address envelope. So it just said, address, comma, address, city, state, zip. They sent out 50,000 of those, where that was the return envelope address had.

So ACT UP: so I –

SS: So whose idea was it to do it for ACT UP?

SEAN STRUB: Peter Staley called me. I had, you know, followed ACT UP in the papers, in early 1987. I was focused on the action in front of the White House, which ACT UP wasn't initially a part of, and then ended up – because they weren't even – it was in January when that really started. The International AIDS Conference was going to be in Washington; and the Book Study Group in Los Angeles, which was Jean O'Leary, Mixner, Scott Hitt, Diane Abbott, Roberta Bennett. Much more activist political energy around the epidemic, in terms of focusing on Washington from there than from New York, which is another thing.

They were talking about doing something at the demonstration, at the conference. And they were all talking, kind of encouraging that we were going to do civil disobedience. And Marty Delaney got onboard with that pretty quickly. And by that time, most of the national groups were clients of ours, in one way or another. And so I was tasked, or one of the tasks was to try and get the executive directors of these groups to agree to get arrested. The idea was going to get the whole leadership arrested at an action in front of the White House.

And a couple months before, Tim Dlugos and I had been working on – we were going to do a thing at the White House, where we had a whole plan where we

were going to take a pill every half hour until Reagan met with us, and chain ourselves to the White House gates. And we were telling Jean about it, and we were – we were mostly joking, but not entirely.

But there were a lot of people, at that point. The guys in San Francisco had been doing their thing in front of the Federal Building; David Summers, I think, was the first arrest in AIDS-related civil disobedience around the New York City Council hearing – and that was in ’85.

So this stuff – and the Hardwick decision, in the summer of ’86, was enormously important in kick-starting AIDS activism, taking AIDS activism to the streets; but I don’t think has really been understood. The Hardwick decision came out in June of ’86. It spontaneously pushed people in the streets. There were demonstrations all over the country. And for the vast majority of those people, that was the first time they’d ever demonstrated publicly around a gay issue.

SS: Huh.

SEAN STRUB: And that, I think, kind of paved the way for the civil disobedience that happened over the next several years.

So at the action in Washington, June 1st — May 31st and June 1st — there were all these ACT UP guys there. That was the first time I saw Stephen Gendin. And a few weeks later, Peter Staley calls me, introduces himself, and very businesslike. He says, I understand you’re the direct-mail guy. I’d like to come talk to you. And he came with his briefcase. I think he had a jacket and tie on. And I think there’s only

five years difference in age, but at that time, it seemed like he was a lot younger than I was, right?

And I was like – welcoming of ACT UP. Be like, read this, great, go get them. But it was also a little bit like, where have they been? You know. It felt very arriviste, heh, for this. It was like, you know – not that we weren't appreciative, but it was like, all right, and they're getting all this attention and stuff.

And I didn't think of it in terms of an organization; it was just something that kind of spontaneously happened. I didn't think of it as – that kind of advocacy was clearly, there was now a place for that, but I didn't – it wasn't branded, ACT UP, as this new thing.

SS: Right.

SEAN STRUB: It was just a community kind of –. And so Peter comes and talks to me. And I'm telling him – that – I wasn't understanding the purpose of it, other than demonstrations. I didn't see – how can you raise money – there's no organization here. And then he described how this will never work. Direct mail is, requires a real understanding of the process; it requires a long delay. You can't think just to the next, you know, action. I don't think we were calling them that yet. But I
01:45:00 sort of explained the mechanics and the economics of it; and said I'm come to a meeting. And came to a meeting, was sort of captivated by it. And then he wanted a proposal. And he said, you know, he would deal with the Fundraising Committee, and so the whole thing. And so we did the proposal for an initial mailing. And it was a

client. And we were doing a lot of stuff for free, but they were absolutely a client. But it was exciting. I mean, the first time I was at the meeting was like kind of cool.

But it was a big problem, because it wasn't – constituted as a nonprofit, so we couldn't get a nonprofit rate. Which changed the, made the economics more difficult, because the commercial bulk postage was about twice the nonprofit bulk postage.

And so we did our proposal, and the letter was going to be signed by Harvey Fierstein. And – I honestly can't remember – if they paid for it in advance? Or – I know that the big mailing with Keith Haring, Keith put up the postage, and we guaranteed everything else. I can't remember if we did that, the first one, with the Harvey Fierstein or not. But I remember – at that time, I was using a lot of newspaper clippings as an insert. A lot of direct-mail things, they have like a brochure. Except who reads brochures, you know? If you have something torn out of the newspaper, people read that, it looked like. And then I'd do a little yellow highlighting printed on top of it.

But that was a problem, because newsprint comes on rolls, and direct-mail pieces are printed on flat sheets; and roll paper is very thin, and it's oily, and it messes up the folding machines and stuff. But I found a guy who had kind of like a fake newsprint. And then we figured out a way to run it in the cutter – we had a wire. And the wire – sort of cut around this wire, which gave it a little bit of a rougher edge, rather than a sharp cut. It looked a little bit more like somebody might have torn it out of the paper.

And I forget what the article was – an article about one of the ACT UP things, from the *Times*. But on the back of it – I always printed something on the back, right? You tear something out of the newspaper, it's not blank on the back; it has something on the back.

And so on the back of it, I took a section from the theater page of the *Times* – because Harvey's play – *Safe Sex*, I think was running. And so you could see, about two-thirds of his ad of the *Safe Sex* thing, on the back of it. I thought it was like great free advertising for him.

And that was the first piece we did, and I think it was 50,000 pieces. I don't remember how much it raised, but it raised a fortune. It was immensely profitable –

SS: When you say "a fortune," I mean, I know we're talking in the 1980s, but what would be about –

SEAN STRUB: Well – for acquisition mail, which almost no one could do on a break-even basis; right? The big national groups would have to invest money to get donors. But sometimes these niche things, if you had targeted lists that were good enough, would work well. So it was 50,000 pieces, and assuming it was 50,000 pieces, it was probably – the cost was probably roughly – 18 or 20 thousand dollars. This is – totally off the top of my head, but I think it took in at least like 30. I mean, it was –

SS: Right.

SEAN STRUB: – it was at least –

SS: And that was what year?

SEAN STRUB: I thought it was ’87. Peter tells me it wasn’t until ’88. But I think that is because I broke my leg on July 4th, 1987, and was out of commission for about six months. So I think we started talking about it in the, maybe fall, summer or fall of ’87, but the mailing didn’t go out until early ’88.

SS: So of those 50,000 pieces that you sent out, like, which lists were good for ACT UP?

SEAN STRUB: Okay. So ACT UP didn’t have a list. Right? And the best lists are the ones that are not commercially available, you can’t go out and rent. You would swap a one-time use. Right?

So, like the Task Force, and SAGE, and things like that. They didn’t rent their lists. They would only make a part of their list available to another group who had a list they wanted to mail. Right? It was a reciprocal exchange.

ACT UP didn’t have a list. So in some cases, we could use our in-house database as a list that we would say, well, we’ll swap that to you for that. And by that time, we had been doing some of these programs where we were financing the acquisition mail. And part of the deal in financing the acquisition mail is the data that came back was shared with our database.

SS: Right.

SEAN STRUB: So it was not only, you know, you’re SAGE; you get your 25 dollars, and you get somebody’s name; we also got that information in our
01:50:00 thing, unless they checked the “do not share my name” thing or whatever on that.

And so we were creating a real depth of data. So by then, I was doing a fair amount of mail for a lot of AIDS organizations. So I knew not only people who specifically were giving to AIDS, but in some cases, people who were giving to more than one AIDS organization. Or in some cases, people were giving to AIDS – and I would do things like get the Federal Election Commission reports for not just gay candidates, because there weren't that many then; but officeholders and candidates I knew were gay, but were not publicly so.

So I would get Gerry Studds and Barney Frank and Pete Kostmayer and Stewart McKinney and all these other. And then I would even find some common names on them. I identified a whole social circle that was very closeted, of people who were actually giving to these guys — who were very closeted — giving to closeted members and candidates. And so we'd overlay that data onto it.

So I could identify somebody who was giving to AIDS and giving to a political campaign; and that was a pretty good prospect for ACT UP.

The GMSMA — the Gay Male S&M Activists — had a list of thirteen hundred names. Not a very big list; but an incredibly responsive list. And a very high average gift, and a very affluent list. If you mail 10,000 names, and you get a one-percent response at a twenty-five-dollar average gift; you know, that's the same amount of money you're taking in as if you mail a 5,000-name list, and you get a two-percent response, and a twenty-five-dollar average gift. Or you get a one-percent response and a 50-dollar average gift.

People say, what's a good percent response. And it's not; it's really a function of the response and the average gift, and what it costs you to send it.

So we would calculate it in the CPM and the RPM: the cost per thousand pieces mailed, and the revenue per thousand pieces mailed.

And back then, a lot of lists we wanted wouldn't allow anything AIDS to be mailed to them. International Male; Williams-Sonoma; the companies owned by gay men; and some of these very hostile responses. So that was another whole battle we had within the direct-marketing industry, and we were – but – so –

SS: So how many of these did you do for ACT UP?

SEAN STRUB: There were two – there were two packages we created from scratch that I remember. One was the Harvey Fierstein one, that I put the Silence Equals Death logo on the outside of the envelope. Because then – because we couldn't put "gay" or "AIDS" on the envelope. So I was always finding ways and euphemisms, and you know, design euphemisms to sort of communicate something. And at that point, the Silence Equals Death logo – a lot of our target market sort of knew that was about them. And we put it on there real big. We got some complaints, but not too many. But most other people didn't know what it meant. It wasn't outing them to their mailman, you know, which is what people freak out about.

So that; and then the Keith Haring letter. So the Harvey Fierstein, we did the first mailing, and then we did a much bigger rollout. Because that's what you're –

SS: Oh, okay.

SEAN STRUB: – really looking for, is being able to roll it out, and get many more names. I think there might have been one or two or three, we call them action alerts, which was a preprinted form, that all we did was the copy for, and send them to a place that just lasered them and sent them out. Would go to ACT UP's existing list. Because then they had a list, they had a couple thousand people who'd given them money through the mail before. They were people good to go back for. But those were just little projects, from our perspective.

SS: And what year was the Haring one?

SEAN STRUB: Keith Haring one was in the fall of 1989.

SS: So by that time, ACT UP must have had a big list, right?

SEAN STRUB: Not a big list, no. No. No, because it wasn't keeping names, it wasn't gathering names anywhere, except from our mail program. So, you know, I don't remember what we did with the Harvey Fierstein thing. But if we did 50,000 pieces initially, and I think we might have done another hundred, another two hundred thousand pieces; ACT UP maybe had two or three thousand names, you know – something – that's a lot more than nothing, but it's not a huge list.

SS: So by 1989, they only had two or three thousand people on their mailing list.

SEAN STRUB: Of people who'd given them money through the mail before.

SS: But what about our own list?

SEAN STRUB: Well, that's what I – I don't remember any other list. There might have been some internal list of some size; maybe people, you know,

01:55:00 signing something. But I don't remember. There might have been a tiny list of people who'd ordered merchandise through the mail.

SS: Okay.

SEAN STRUB: But we weren't doing petitions, which was one good way to get a – we didn't have a mailing list, we weren't sending things out from ACT UP.

SS: Right.

SEAN STRUB: It was all material at the back of the room.

SS: So by the time of the '89 one – so you said the first time – you sent out a 50,000 piece, and then you did some rollouts after that.

SEAN STRUB: Right.

SS: By the time you did the Keith Haring one, do you remember how many people were responding?

SEAN STRUB: I remember the Keith Haring mailing – I was so confident in it at that time – mostly because I had so much more data on my list at that time that to a certain extent, we could almost guarantee. We could take the ultra-multi-donors to AIDS things and political things, or whatever — it wasn't a huge group — but we knew those would be profitable, and that would give us some insurance when we were going to the more-marginal ones, that were really a test, that we didn't know.

SS: Right.

SEAN STRUB: And Keith's career was just so, you know, exploding at the time. And initially, he was going to come out about being positive in this letter. That was the first time he was going to go public.

SS: Oh.

SEAN STRUB: And I – let's see – I talked to him in like June, briefly, but he didn't have enough time to sort of really talk about the letter. And so then, I saw him in either June or August, in Paris, at his hotel. I was there, and he was there at the same time. And I actually recorded an interview with him – and sort of explained the process. And he told me some art magazines that he thought he could get, because those were all lists, they were expensive lists, but they were available; subscribers to *Art in America* or something. Pretty affluent profile, right, on that as well.

And I remember asking him: I said if we had this universe of whatever thousands of people, and they were all in a room and you were standing up there, what would you want to tell them? And we talked about that. And drafted the letter. Then went over the letter with him in New York, and gave him the specs for the envelope, and what we needed.

And that was when customized laser technology was just new. And I had a friend who was selling this for a mail shop in Virginia. And he had been trying to get me to do something with a handwriting font. And he had all these different handwriting fonts, right? And he had names for them: the Little Old Lady font; the Catholic School Penmanship font. And I said, can you make a font? And he says, yeah, how do you think I did these.

I said, could you make like some individual's font? And he said, sure. And I told him I wanted to do a font in Keith Haring's handwriting.

And he told me what to do, and gave me these grids to write off of. And Keith was like totally into it. He was like so cool. And so we did the whole thing, and we wrote out. And then we had to do the punctuation marks, and everything. And so we digitized all those individually to create the laser font, so the address would be in Keith's handwriting, right? Which is distinctive. Even though it was clearly a direct-mail piece — it had a window envelope, the address was showing through, it was on that, but it had his graphics on the outside.

And he did the poster. You know, I wanted like a premium, that people gave a certain amount, we would send them something.

And originally, he wanted to give us little plastic condom cases that he had had made, he was selling at the Pop Shop, and they weren't selling, so he had a lot of them, basically, he said.

And I said, those are great, but we'll need more than whatever few hundred that he had. I said, we really need something we can like print and send out. So then he did that big Hear No Evil See No Evil poster. And I think if you gave 50 dollars, you got the poster.

And then, while we were in the process of finalizing the production on it, he had given an interview to *Rolling Stone*, and came out about being positive in *Rolling Stone*. It was a huge, huge news story. It was just a couple weeks before our

piece was going to mail. So I knew, when you can coordinate something with media like that, it's like unbelievable, it can be, just do huge things to response.

So that's when I said, you know, let's just go for it, and mail 200,000 pieces. But of course, ACT UP didn't have either the capital to put into something like
02:00:00 that, or, as a group, probably, the ability to sort of understand the economics of it, without people going crazy. And I was dealing with Peter on it. And so I said, if you can come up with the postage — because that had to be laid out upfront — that I would guarantee the printing and letter shop and list bills. And these were a lot of expensive lists. We used a lot of art lists and a lot of other lists beyond the ones we could exchange for or that we had ourselves.

And so we did. And it was incredibly successful. I don't even remember how much money it made.

SS: But can you just guess?

SEAN STRUB: I'm not even sure that I know. I think we required that the responses came back to a lockbox, that we picked up. We couldn't deposit the checks, but we picked up and processed them, and then here is a batch of X checks, and then ACT UP gave us a check for that till the bill was paid off. And then I don't know how much continued to come in.

The tail of these mailings – typically – for stuff that is mailed out bulk rate, which ACT UP's was: from the date of your first response, which typically will be about two weeks after you drop it in the mail; at 12 or 13 weeks out, you're at about 90 percent of the response you're going to get. But then the other 10 percent will come in

over the next 12 or 13 weeks. So they can have a very long tail in the response. But at a certain point, after our bill was paid, we didn't have any role in it.

SS: So you must know, approximately how much did ACT UP make on that.

SEAN STRUB: I actually don't remember, on that one. I really don't. Because – first of all, that year, my partner Michael died in December of '88. And that was my – so the whole 1989, 1990, 1991, I was like on some adrenal autopilot that I – it's amazing, what I don't remember. And then St. Patrick's was that December.

SS: Right.

SEAN STRUB: So I don't remember. I know it was very profitable. I know ACT UP ended up with a list – I want to say that by the end of that, ACT UP's list was around six or seven thousand –

SS: Sixty-seven thousand.

SEAN STRUB: Six or seven thousand –

SS: Six or seven thousand –

SEAN STRUB: – records. And just kind of off the top of my head, there were maybe 2,000 or twenty-five hundred from the Harvey Fierstein mailing. Maybe – let's see – the Keith mailing – that wouldn't have done 5,000. It wasn't a two-percent response, but it was well over one percent. So it was probably – three, four, maybe five thousand responses. And the average gift – I want to say it was like in the mid-40s. Because the $50 – if you gave $50, you got the poster, right?

SS: Right.

SEAN STRUB: So that really brought the average gift up. The average gift, for most of our gay- or AIDS-related acquisition mail would run 23 to 28 dollars. The more substantative it became; if it was something more policy-oriented, like Lambda, where you're really getting into detail, right; the average gift would go up a little bit higher. The more it was about care-provision and service, the average gift would go down. But I remember ACT UP was a really, really high average gift.

So say there were four thou– I'm just picking numbers. But if there 4,000 responses, and the average gift was $45, that would be $180,000 that came in. And the mailing — and I'm kind of guessing at these numbers — but the mailing, 200,000 pieces, was an oversized thing; the laser font didn't cost that much more; and it was commercial bulk postage; so it would have been less than 50 cents a piece. So it was less than a hundred thousand dollars for that.

SS: And then what was your fee?

SEAN STRUB: Uh, well that was built into it. So –

SS: Oh, okay.

SEAN STRUB: – in terms of what we made on it; I'd have to go back. If we did well on it, it was maybe $20,000.

SS: So ACT UP got to take –

SEAN STRUB: Oh, excuse me, wait a minute, no. No, on the Keith Haring one, we didn't make any money. We were doing that as a volunteer thing. The only one we did for ACT UP that we made money on was the Harvey Fierstein one, was the initial one.

SS: Okay.

SEAN STRUB: After that, it was all –

SS: So ACT UP actually –

SEAN STRUB: We, we got – excuse me, but we –

SS: I'm sorry –

SEAN STRUB: – we got the data. So we made –

SS: Yeah –

SEAN STRUB: – we made the –

SS: – no, I understand.

SEAN STRUB: – advantage of the data, which was very useful, good
02:05:00
data for us. But it was also our data that reduced the risk enough to make it worthwhile, make it –

SS: No, I understand.

SEAN STRUB: – reasonable proposition.

SS: But so ACT UP actually got to take about 40 percent of the money. That's **kind of amazing.**

SEAN STRUB: Yeah, it might have even been more than that. I really don't know what the thing was. And all the mail for ACT UP was so way, way out of anything ordinary in direct mail, in terms of the economics of it.

SS: So now you did, I think, two major AIDS-related businesses, right? One was *POZ*, and one was the drug-delivering system, with Steve. What was the name of that?

SEAN STRUB: Community Prescription Service.

SS: Right. Okay. CPR – no –

SEAN STRUB: CPS.

SS: – CPS. Sorry. Okay. And which one of those came first?

SEAN STRUB: The prescription service. But what it really was –

SS: Oh.

SEAN STRUB: – the prescription service was, really came out of the card packs. So –

SS: Oh, uh huh.

SEAN STRUB: – started doing the fundraising mail. And in order to do the fundraising mail, I needed to find more lists, because there weren't commercially available lists. So first, it was working with all the boards of directors, for them to understand how they could control swapping their lists. They could be sure somebody, everybody would decoy it and protect it and make sure somebody didn't steal it. And then how it was in the interest of their organization to swap, particularly with, the more like-minded the organization was, the better.

The best swap for Lambda was GLAD in Boston, or National Gay Rights Advocates, the groups they also kind of thought of as their competitors, you know. So the more competitive something was, the more likely their list was. You'd say, you don't have to give them the people who just gave you money six months ago. Give them the people who don't give you money anymore. You know they were once

interested in you. For whatever reason, they're not giving to you anymore. Maybe they'll be interested in the others. You know, so –

SS: Right.

SEAN STRUB: – kind of teach them that process. That doesn't mean you have to turn over your firstborn or your very, very best names, or something like that. You just had to be honest about what you were providing.

Like with magazines, you can rent the expired subscribers. That's cheaper than renting their active subscribers, right? So working with those boards to get them to swap, and then creating our own database, and going to all these gay businesses — the travel agencies and the club promoters and the petition-signers; all that stuff — to create a database.

And then, I had this database, right, that I was using for our fundraising clients. But increasingly, we were getting commercial things that wanted to rent it, right? Whether they were gay businesses, marketing whatever; or non-gay businesses, looking to come into the gay market. Because when the gay market started to be seen as a market by mainstream businesses, a lot of them, they weren't ready to go on television. They didn't want the rest of their customers to see it. But direct mail enabled them to appeal to LGBT consumers without letting anybody else know.

SS: Right.

SEAN STRUB: Because it'd show up in your mailbox, just right there. And so AT&T – and so we'd have these – so I started the little card pack thing, right? And we were –

SS: What year is that?

SEAN STRUB: Eighty – I'm sorry, '87 or '88.

SS: Okay, so –

SEAN STRUB: I could find out. I think I saved – I have a file of my –

SS: That's **okay>**

SEAN STRUB: – little card pack messages. Which I think was also, you know, in retrospect, partly driven by me. I was in this sort of peculiar position, because the Task Force and NGRA – all of these groups – I was a very, kind of important part of their fundraising, right? And they largely deferred to me. If I'd tell them something would work, you know, they were looking for money; they generally would say so. I'd open up the *New York Times*, and I'd see a story, and see how that translates and we could do that, if we could get something out quick.

With NGRA – so when – I started when Jean O'Leary was head of NGRA, National Gay Rights Advocates, which was a San Francisco-based legal group. And when I started with them, their donor file had five- or six-thousand names. Ninety-three percent men. And it was a legal thing and it was largely regional.

And Jean was very aggressive and very ambitious in changing all this stuff, and was really into – the two clients I've ever had who were most sophisticated about direct mail fundraising: Ann Richards and Jean O'Leary.

SS: Huh.

SEAN STRUB: Who both of them – they could remember the response rates to a fraction of a percent, and average gifts, and come up with ideas to increase the average gift to something. It was actually pretty amazing.

And Jean was the client I got, that we did this sort of test on comparing
02:10:00 the cost of, the lifetime value of men giving to NGRA versus women. Because when we'd mail women's lists; when we started to get them; we'd just select the female names off of some other list; sometimes the response rate was the same as with the men, but the average gift was lower. Logically, right? But, what I think – I don't even know if I was guessing, or if I had observed it anecdotally, or was doing some analysis, and figured it out; but the whole point of it is not to get them to give that first time. You know, you're breaking even on that, if you're lucky. ACT UP had this weird circumstance that it was making money, because it was so timely and so exciting – and the mail was less costly for them to produce. But most groups were losing money to acquire donors, to create that donor base.

But, I found that when you went back on the resolicitations, which we did for the clients that we were really managing the program for, that about half of the men giving never gave again.

SS: Oh.

SEAN STRUB: They gave one time; and then they went on to some other things. And that's actually not unusual, in direct-mail fundraising.

SS: Now do you think that that's **AIDS-related?**

SEAN STRUB: No, this was just in general, around –

SS: Oh, you think –

SEAN STRUB: – direct-mail –

SS: – it's **just –**

SEAN STRUB: – fundraising –

SS: – gender.

SEAN STRUB: I did the whales, you know. I'm going to do seals next time.

SS: Oh, okay, okay.

SEAN STRUB: It's very typical that a lot of the people who give one time – you know, maybe they wanted the book bag. They don't want another book bag. But I noticed that the women, on the resolicitations, were responding at a higher rate than the men. So when you looked at it in a window; after about three years, the women we were acquiring up here were actually more profitable, long-term, than the men. Because the women was a relationship, more often, you know, with the organization. And the men, you know, their attention went elsewhere.

SS: But these were gay women and gay men?

SEAN STRUB: Yeah, yeah.

SS: But do you think that the men's **giving patterns was related to AIDS?**

SEAN STRUB: No.

SS: No.

SEAN STRUB: Well, I mean – sure, and they were caring about it. But it wasn't that they were dying, that therefore they weren't giving anymore.

SS: Or that they were involved with caring for other people, or anything like that; their money went other places.

SEAN STRUB: Well, I mean – I don't know. I mean, I didn't look at, I didn't think of it in those terms at the time. Because I mean, the women giving to these things were involved in lots of things, too.

SS: Okay.

SEAN STRUB: There are a lot of donors who have a short attention span, right? They give in the moment; it's just an impulse. They – they get home from work, and – you know, they were, they're reading the letter, and it just moves them, and they do it. Or they have a little extra money that month, or they, who knows. I mean, there's all this wonderful and interesting analysis on why people give, and who gives more.

Roger Craver did an analysis of direct-mail donors one time that I still have around here somewhere. Jews give 13 times the average through the mail. Because there are different cultural traditions around giving. Right?

SS: Right, you're required by your religion –

SEAN STRUB: Catholics give much more through the mail than Protestants. If I could delete Protestants from my prospect lists, I'd do so. And it also has a lot to do with how long your family's been here. So first generation, in certain – second generation – you know – their lives, their families, they're getting established.

They're not giving to change anything; they're just trying to cope with this world they're living in. Once somebody's been here five generations, they're so vested in the status quo they're not giving to social-change organizations. It's really from that third and fourth generation Americans who are the best prospects for giving to social-change organizations.

And the donors even to radical groups, right or left, don't think of themselves as radicals. They think of themselves as the middle of mainstream rational thought.

SS: Now what year was CRS started?

SEAN STRUB: So I started the card packs, right?

SS: Right.

SEAN STRUB: And in the card pack, we would have other advertisers. So we had various mail-order pharmacies who were advertising in the card pack. Because people didn't want to go to their local pharmacy, there were privacy issues, there were access-to-the-treatments issues, even with ddI and ddC and things like that. And, importantly, most of these mail-order pharmacies were waiving copayments routinely, just as a matter of course, which technically they aren't supposed to do, but they were doing it.

SS: Because they perceived that people couldn't afford them?

SEAN STRUB: No, it was a marketing advantage for them.

SS: I see.

SEAN STRUB: They were getting paid enough by the insurance company that it was wildly profitable. In many cases, they were charging these
02:15:00 ridiculous amounts, that the 10 bucks, which was what a typical – five or 10 dollars was the typical copay — a Bigelow's, and places in the Village, if you knew them – Village Apothecary was great for waiving copays routinely. You just had to ask for it. Probably not the case, though, for somebody in Iowa City.

SS: Right.

SEAN STRUB: And so there was one advertiser, from Ohio; and they came to us one time, and they were advertising. And they said, you guys should be the ones doing the marketing. And you know this community, and yada yada. And Mike Erlenbach, his name was. And they had a pharmacy, a mail-order pharmacy, in Ohio. And I was not interested in it, quite frankly. And he was insistent. And I was polite to him, because he was a good advertising. And Stephen was running the card packs. And Stephen was more interested in it in general, and so at that time, Stephen worked for me for a couple years; we were kind of trying to find something to be sort of his own project, rather than sort of just assistant to me. Or talking about the direct-mail fundraising, and this and that. He had been mostly doing the list and fundraising work. And he'd taken over running the card pack. And he said, this guy really, he'll put up some money. He'll finance, it won't be any risk to us.

And so finally, he went back and forth. And we said that if he would finance a newsletter — that we would use a newsletter as our marketing device — sure,

we would give it a try. We didn't have anything to lose, they were going to pay all the expenses. And –

SS: This Ohio –

SEAN STRUB: This Ohio firm.

SS: Okay.

SEAN STRUB: Because Stephen — I don't know if he was the editor, or whatever, of the *Treatment Data Digest* at the beginning of ACT UP, which was the first kind of newsletter for, you know, consumers – consumers is the wrong word, but – it was written for people who might be actually taking the drugs. And so I think he wanted to do that in a broader way, through this newsletter thing.

And I said, well, what if we, you know, let's just do it, for one issue of it. And it doesn't work. And I said, I want to make sure we have enough money to do it for a year. And so we negotiated. And they agreed to finance $75,000 for our marketing activities, which was an enormous amount of money. And I think, god, that'd be great, that'd pay for most of Stephen's salary for a year. It was a time when financially it was stressful.

So we did it. And started. And Stephen owned part of the company, and he ran it almost entirely himself. And – it became profitable. And we started out – this whole Community Prescription Service, it was Community Card Pack. It was sort of like, jumping all over the "community" word.

And we had an advisory committee. And it was Peter Staley, Phill Wilson, Connie Norman — I don't know if you ever knew Connie Norman or not, she

was fantastic — Michael Callen; there might have been one other person. And they were our advisory committee, and they're in our brochure with their pictures, and they said something nice about it. I think we paid each five hundred dollars.

And the – what was attractive and made it competitive was, it was owned by people with HIV; we routinely waived copays; and very importantly, we would go to bat with the insurance companies for – because all these, there were all these treatments coming out that insurance companies wouldn't cover, wouldn't recognize, or it was trouble. And Stephen was brilliant at that.

And so it wasn't somebody going to their local pharmacy in Iowa City, who only has so much time to deal with insurance company; we'd have 10 or 15 customers looking for this drug – and Stephen would know where to find the papers that were being published that suggested this would be useful.

And people called. The customer service office was right in our office. And people called all day long, and then it'd be sent out from Ohio.

SS: And what year was that?

SEAN STRUB: Um – I'm not sure when it started. Eighty-nine or '90, I think.

SS: And that newsletter becomes *POZ*.

SEAN STRUB: Well, kind of and not really. So with the – the

02:20:00 newsletter – initially, it wasn't a newsletter per se. We called it the CPS Info Pack. And it would be material we would find in different places, including at ACT UP meetings, that we would just Xerox. Because what I had been doing since I first started

going to ACT UP meetings is picking up stuff, and the next day, in my office, I would fax it to various friends around the country that it was important to. Just, you know, six people, eight people – it was growing some. But I mean it was like a little fax thing I was doing.

And so then, instead, we started just copying these things, and putting them in a packet, and mailing them out. And very quickly, it was hundreds of people, because that was like, the marketing thing for the prescription service. And anybody, whether they ordered from us or just asked for the newsletter, they got it. And then it became cheaper to actually produce our own newsletter, rather than Xerox all these other things. And Stephen, which would put it together. And some really wonderful things.

Remember when all those nutrition bars came out? Suddenly, right? And they were all over, everywhere? Stephen – I forget – one of them, whatever it was called, immune-whatever. And he did an analysis of the ingredients. So then we came to the conclusion that a Snickers bar with a multivitamin gave more nutritional value at half the cost –

SS: Oh, god.

SEAN STRUB: – of the other one! We wrote, we did things like this in the newsletter that were really kind of fun. And –

SS: Here's the mys – oh, I'm sorry, go ahead.

SEAN STRUB: So that's what – I kind of – my – you know – role around, like, providing information around the epidemic really started with fundraising.

Because when you look at those fundraising letters we did, very few of them were sympathy appeals. They were some of the best, most-current, cutting-edge, relevant information, at a time when the *Advocate* had a circ of 45 or 50 thousand, we were sometimes mailing out 300,000 pieces to mostly gay men around the country. Had a tremendous sort of circulation.

And that's just what I'm talking about my role with the executive directors of these organizations, where they were kind of relying on me, and I felt like I was having kind of a policy role around identifying the things that would work for fundraising — which is its own risk with them as well — but also using the fundraising to get out information about treatments, about testing, about prevention, around all those things.

And so then more specifically, around treatment; I kept, even though we had this newsletter, I'd talk to my mother, and she'd ask me if I saw that article about Brazilian tree algae, or something like that. And so I started thinking about something that would create a larger sort of conversational ballpark; something that not just the science club members, or people who went to ACT UP meetings or whatever, would relate to. And thinking like – like a *People* magazine, but just of people with HIV. Because in the media, every time the epidemic was referenced, it was inevitably fatal, dread disease, no survivors; a hundred percent terminal, yada yada yada. And yet, in my life, which was surrounded with people who had HIV, and all these incredibly vibrant people leading really interesting lives, despite this life-threatening challenge.

I actually had a client, Eileen [Rockefeller] Growald – the Institute for Mind-Body Research, or something like that [Institute for the Advancement of Health]. So I was doing all this stuff for these fundraising letters around her about mind-body stuff that was interesting to me, and I, you know, if – we know that when we get a feeling in the pit of our stomach, or cold feet, or the hair on the back of our neck rises, that that's some kind of physiological response to some sort of intellectual stimulus, whether fear, anger, whatever it is. And it just seemed logical to me that the immune system had to work in some similar way. And if it was assaulted with death-sentence messages, you know, it just isn't going to try as hard; as opposed to having the benefit of all these examples I had in my life.

Literally, *POZ* was started just to talk about the people that were populating our lives, in our activism every day.

SS: So here's **my question. So you have this – I mean, it all sounds like it would all work perfectly. You had this brilliant mailing list, that you've pulled together, that is perfect for something like CPS. You have this sponsor. You have this advantage to the clients, because their copays are waived. And you're working with the insurance companies, and you have this – so what happened to CPS? What –**

02:25:00 SEAN STRUB: When Stephen died – I, I honestly was never that interested in the business. You know.

SS: Oh, okay.

SEAN STRUB: I really and truly wasn't. And I'm always someone who has been a reluctant treater. I've always seen pharmaceutical treatment as not the first option, but the last option. And in fact, one time, Stephen was really angry with me – the really only one time that we really – we didn't have words, but I knew he was really, really, really pissed. Was in 1990 – during my campaign – and Stephen was running the card pack, pretty much, without much oversight from me. And he took an ad from Burroughs Wellcome, that was promoting their Buddy campaign. There were billboards all over, and bus ads. And it showed some forlorn-looking guy. And it was about promoting people to get tested – right?

And you called this number; and they would send you to a testing center that Burroughs Wellcome was funding. But they were only funding testing centers that were recommending people go on treatment right away.

SS: Right.

SEAN STRUB: It wasn't a campaign about getting people tested; it was a campaign about getting people on treatment.

So Stephen takes the ad in the card pack. I see it. And I'm, you know, I felt like shit. I'd never take that ad. I don't believe in that. I'd already been critical elsewhere about this campaign.

So the next card pack, I wrote a whole thing, saying, I wouldn't have taken that, because that campaign is not about getting people tested, it's about getting people on treatment, and I think that testing and treatment are two separate things; that you shouldn't assume treatment if you go and get tested.

And that was very important to me. And I felt compelled to do it. Stephen didn't want me to. It would embarrass him. And it infuriated the agency that placed the ad, and they were actually kind of abusive at the time. And then Chuck Ortleb, you know, runs a whole story about card pack publisher trashing, you know – he takes it off in another direction.

So Stephen largely ran that business by himself, even to the point of setting his own salary. And it became profitable. And it was an important part of the funding for *POZ* – not the most important part, but certainly one of the three most important parts of funding *POZ*, initially.

And when he died – you know, I was devastated, and just wanted to get rid of it. And, sold it, for a pittance.

SS: Who did you sell it to?

SEAN STRUB: The company called – so the company we had been dealing with in Ohio got sold to a company called MIMS. And actually, the year before we sold it, they were the single largest advancing by percentage share on the NASDAQ, the entire NASDAQ. And looking back, I think that part of that had to do with this incredibly profitable business they had with us. It was vastly more profitable for them than it was for us.

SS: I see.

SEAN STRUB: And not long after Stephen died, they offered to buy it from me. And I made sure they'd keep some employees and so on, and sold it.

SS: Now *POZ* could have – there was a certain kitsch to these kind of famous pharmaceutical ads in *POZ*, right? Where like the guys were completely ripped, and they were gorgeous, and they're climbing mountains, and all that kind of stuff, for various drugs. I mean, how did that whole aesthetic evolve?

SEAN STRUB: Well, the first direct-to-consumer ads, where sort of an AIDS media emerged, right? — with *POZ*, there was *Art & Understanding* that preceded us; and then something out of Chicago — and they'd go to the pharmaceutical companies. They were treating them like journals. And they would put the same ad in, if they advertised, that they were putting professional journals. So it would be a molecule or something. I mean, some very technical kind of thing.

And then, when they started to realize that there was a sort of consumer market — because it was before DTC [Direct to Consumer] advertising was so big as it is now; it was just kind of the beginning of it — and they would start to create ads specifically for a consumer audience. And the first ones were very kind of dark and sad – they'd have somebody walking along the beach, looking up at the moon, you know.

And then, the first ones where they were like showing somebody who
02:30:00 was represented as a person with HIV; and then they'd have their little disclaimer, that they were, this is not an actual person, it's a professional model, or whatever and that, I just could not stand that. And so we wrote something about it in *POZ*, one of the very first issues of *POZ*; we said, you know, if you're someone with HIV who's willing to

be a model in one of these ads, let us know. Right? So lots of people with HIV who could use the money, and I thought it was just contributing to the stigma, right?

So we got 50, 60, 70 — Megan would probably know — people who were delighted to, eager to do this. And we gave them to a modeling agency in California that created a positive models division, or whatever. And then they started supplying them to the companies.

And so then they were using real people with HIV for a while. And then, the next kind of breakthrough was really the Crixivan ad, which was the rock climber. And the irony was that about a year after my health came back, I did go rock-climbing for the first time.

SS: Okay.

SEAN STRUB: I thought I'd take a picture of it. And then, occasionally, they would start to show ads with somebody in a social context – either with a group of people. I remember when Marinol, they had a problem with that, because they created an ad that's a synthetic marijuana; I forget, that Unimed, I think, made – but when that was introduced, and the FDA wouldn't approve the ad, because it showed a group of people, and implied it might be in a social context. So they had to go back to just one person yet.

But then sometimes, they'd show two, and eventually they evolved, and actually showing, like, two guys represented as a relationship, or whatever like that. So there was kind of this evolution. And then they've now gone back to models, although

they don't necessarily say that anymore. You know, the whole real people thing has kind of gone away.

The custom that emerged in the publishing industry with direct consumer advertising, pharmaceutical advertising, was that the required prescribing information — which could take another page or two, right — is that most publishers discounted that dramatically. And Megan made an argument to the agency, we weren't going to discount it, because our reader read that stuff, and we want them to read that stuff. So then we actually got Crixivan, a couple of others, they redesigned those pages. So instead of little teeny tiny mouse type, just black and white, they'd have headers, they'd use color. We'd say, this is good for your product and your whole thing if you're actually saying this is information you need to know and you need to understand.

The problem with direct consumer advertising is pharmaceutical advertising, is it creates, in my view, sometimes inappropriate demand. But the other side of it is, it also, in this instance, with HIV meds, alerted huge numbers of people to the fact that there was treatment available and contributed greatly to mobilizing and politicizing those communities to demand treatment, for things like ADAP programs, and stuff like that. I'm not sure those would exist as they are today if it hadn't been for the direct consumer advertising alerting communities –

SS: Well, for them to custom for your magazine must have shown that they knew that it was very, very important placement.

SEAN STRUB: Yeah. And it was also something very important with the magazine from the beginning was that we would call, trying to sell advertising – first of all – there were no AIDS drugs in the first year or year and a half of *POZ*. That was not a part of what we were intending to do or what we ever even really thought about. It was DTC advertising was so new then. It was really card pack advertisers that we were looking at. We were looking at mostly gay advertisers, who all dropped out very quickly when they realized the magazine wasn't just a gay audience. They weren't interested in the other stuff.

So if you look in the first issues, we had Perrier and Benetton and a lot of gay community things, and stuff like that. And those all kind of went away. But then as the viatical advertising and the pharmaceutical advertising –

SS: Oh, viatical, forgot about that.

SEAN STRUB: – started –

SS: Yeah.

SEAN STRUB: – yeah, the viatical stuff –

SS: Right.

SEAN STRUB: And –

SS: Did that industry end up collapsing because of –

SEAN STRUB: No, it's bigger than ever.

SS: It's **bigger than ever.**

SEAN STRUB: It's huge. It's out there. Not so much around AIDS; but –

SS: But was there a certain group of people who bought into that, and then lived, and then the company –

SEAN STRUB: Oh.

SS: You sold your policy.

SEAN STRUB: Yeah, I sold three different policies. One to New York Life, that they gave me 93% of the face value on. And that's how I funded *POZ*. The biggest one was to Chubb. And I think I got 70% of the face value on it. And another
02:35:00 one to ITT Hartford, or something.

SS: Wow.

SEAN STRUB: Fifty-some percent, excuse me. So one, like the Chubb policy – so like some companies, the very — some of the conservative, old-fashioned ones — they offered it as an option to the insured, as kind of like a courtesy. They didn't see it as a profit center, initially. So like my New York Life policy; they gave me 93 percent of the value, because they thought I was going to be dead in a short period of time, and it was kind of like a wash to them. And they didn't want to lose money on it, but they weren't seeing it as a profit center.

The Chubb policy was sold to a private viatical company, an investor group, right? So they wanted to get it as cheaply as they could, right, and they would do their underwriting, and figure out how long they thought I was going to live.

And then they sold it to a group of investors. So it is now owned by – I don't know, I think it's like eight or nine people, different entities. It's like, I'm sure like Widows and Orphans Funds, or something like that, in Shaker Heights, Ohio, in

Rocky River, Ohio – who I'm sure are deeply disappointed. And I still get, every six months, I get a little form I have to sign or whatever. Yeah, I'm still here, sorry, you know.

SS: Wow. I only have one more question. Is there anything else that you want to cover?

SEAN STRUB: Oh, I don't know. There's lots we could cover. I wish we had more success with home access testing. Because we would then still have anonymous testing today, which is almost impossible to find anywhere in the country. And I think the loss of anonymous testing, and mandatory names reporting, is, those are the two biggest reasons why we don't have more people aware of their HIV status today.

We could talk a long time about meds. But no, I'm fine.

JH: I just want to make sure that there's nothing specifically about ACT UP –

SEAN STRUB: ACT UP – Sure. ACT UP – I was never that engaged in the internal politics within ACT UP. I mean, I was aware of them. But that wasn't what ACT UP was to me. ACT UP was very important to me. And I guess for a while, it might have looked to others like it was my life. But it wasn't; it was my therapy. I needed to be there on Monday nights. It was very, very important for me personally. I don't even know how many demonstrations I went to. But I wasn't that involved in planning, or, you know, I was a little bit in the NIH one; certainly was in St. Patrick's; and of course, the Jesse Helms condom thing, just really a TAG thing.

But I was never a partisan in any of the internal battles. And actually, the more recent history around that, and people have talked about that; I found a little bit surprising. I didn't realize how raw it was at the time, because I just wasn't paying attention in that way.

I think the St. Patrick's demonstration, to me, when I look back at ACT UP history, I think is unbelievably important. And I'm hoping something might happen to commemorate it. It's the 25th anniversary coming up in a few months. I think that over the next few decades, ACT UP is going to be assessed and evaluated, and all sorts of different things are going to be seen about it.

In some ways, it kind of killed the empowerment movement, in my view. ACT UP – the activism that preceded ACT UP, certainly was more important for me, in my survival and activism than ACT UP – not to diminish ACT UP's importance to me, or my pride in having participated in it, but the whole self-empowerment movement, and the Denver Principles concept and all that, that was really people with AIDS focused on helping each other. That was creating a different system. That was creating a peer-to-peer service-delivery model, as opposed to the more traditional benefactor/victim service-delivery model; that unfortunately, much of the peer-to-peer
02:40:00 service-delivery model that we created has incrementally sort of reverted to the benefactor/victim model that's more dominant.

And we really weren't, in those earlier years, so focused on the federal government or the pharmaceutical industry. We didn't expect them to save us. We knew how they felt about us. And ACT UP really corralled the mounting anger and

fear that was just so palpable by then. But it wasn't focused on people with AIDS; it was focused externally. It was focused on those institutions of power, and trying to get them to do what they should have been doing all along.

And so in that sense, it was very, very, very different. And as time passes, I understand Michael Callen's reservations about ACT UP much better.

I don't think that many people were conscious, certainly not at the time; and even still, I think people are kind of resistant to embrace the extent to which we were really the handmaiden of the pharmaceutical industry. We never did anything that bothered the pharmaceutical industry an ounce compared to the tonnage of benefit we gave them in facilitating the deregulation process – that was critical to my survival. But there's another whole side to it that I think we were blind to at the time, and that we were, I think, manipulated in, in many ways.

SS: How were we manipulated? I mean was it direct?

SEAN STRUB: I think there was a real – I don't have the documents to prove this, but I think at some level, within the pharmaceutical industry, and the deregulation stuff, they saw this as genius; and really welcomed and –

SS: But you just feel that. But you don't actually K-N-O-W it. No.

SEAN STRUB: No, I can't –

SS: Okay.

SEAN STRUB: – but it's also – tell you one thing, there's some – the depth of resources that I guess a lot of this begins with the pharmaceutical industry – in

their planning and their looking ahead, is so far beyond anything most activists ever think about or understand.

In January, the first issue of *POZ* came out in April of 1994. In January, someone who, an ACT UP member who worked at Ogilvy, Adams & Rinehart gave me a copy of a memo that Ogilvy, Adams & Rinehart had written for their client, Burroughs Wellcome, about this magazine Sean Strub is starting, and their history with Sean Strub, and this card pack thing they told about and stuff like this. And I was like – I just remember reading it, and being astonished they had any idea who I was, let alone how much they knew about the magazine and the plans. It was just – that was a very sobering –

SS: But why are you astonished? I mean, AZT was the highest-profit-making pharmaceutical in history. Why are you astonished? You were their major conduit to that exact audience that they needed.

SEAN STRUB: This is before the magazine even started. This is when, you know –

SS: But you had already been that person. You had this perfect mailing list, you're doing all this stuff. Why are you astounded?

SEAN STRUB: I guess I didn't even think they would know that. I didn't think they would have known I existed, let alone had any sort of insight into the magazine I was organizing –

SS: But that may say more about you than about them.

SEAN STRUB: Well, maybe. Maybe.

SS: Yeah.

SEAN STRUB: Yeah, I'm a lot less naive than I used to be, that's –

SS: Yeah.

SEAN STRUB: – in all sorts of ways, that's for sure. But this is why – so when you think about regulatory stuff; there are people that are looking at generational trends, and this kind of stuff. It's like the recommendations around when to start treatment. At one time, I saw projections with different drugs – if the recommendation is to start treatment at 300 versus 350 versus 400, what it translated into the dollar value of these different drugs.

SS: Yeah.

SEAN STRUB: This is like – so –

JW: But you're advocating PrEP a lot. Isn't there a certain shill element?

SEAN STRUB: Oh, I'm advocating PrEP a lot? Heh.

JW: Are you? I mean, I thought you were, but do I have it completely opposite?

SEAN STRUB: Yeah, completely opposite.

JW: Oh good for you.

SEAN STRUB: I'm seen as the world enemy of PrEP.

SS: Okay, well let's **take a minute, and let him tell us. Why don't you tell us why you're the world enemy of PrEP.**

SEAN STRUB: Well, first of all, the discourse in the U.S. around this is so simplistic, and lacking any kind of nuance, and it's boiled down to you're either pro-PrEP or anti-PrEP. And I think – and quite frankly has been driven by AIDS
02:45:00 activists, by treatment activists. And I think that that is, I think we should be ashamed of it, quite frankly.

I have always thought that, as long as I was aware of the concept, the idea, of PrEP; so if you talk to Walter [Armstrong] – you know, one of the things I used to say, when treatment came out, and was so effective; is, and you know, we knew it was effective at reducing viral load, and we were writing about it in *POZ*, about how it was making somebody less infectious, and this needed to be studied. So this was not anything new to us. And even PrEP; you know, I can remember, in the '70s, in the early '80s, going to the baths, and taking tetracycline before, and that was a very common kind of thing. So the concept, you know.

But I would say, treatment is not prevention. Long before we had that phrase, Treatment as Prevention. I always wanted to make this very, you know, distinct between testing, between treatment, and between prevention. And Walter has some strong feelings about this, actually. It's something we kind of disagreed on some then, and still today.

And there is an important role for PrEP – for people who cannot use condoms – some men have erectile dysfunction problems with condoms. People who will not use condoms. Receptive partners who want to be able to control HIV prevention. Receptive partners don't use condoms, they negotiate the use of condoms,

and PrEP gives them some measure of protection they can control. Sex workers. There are places where PrEP makes a lot of sense.

However, the way PrEP is being promoted is essentially as a community-wide recommendation, an alternative to condoms. And I suspect that what's going to happen with PrEP is that it will, four or five years from now, we will look at a lessened rate of transmission among gay men of relative privilege, and an increased rate of transmission among gay men of less privilege. Not unlike what we've seen with unwanted pregnancies throughout much of the **'**90s and early part of this century, where unwanted pregnancies, white women, have dropped, and unwanted pregnancies with women of color have increased.

The irony on this is that I'm being called sex –

SS: So what's **the reason?**

SEAN STRUB: Um –

SS: Because you're saying that more-privileged people have access to –

SEAN STRUB: Will have access. But it's the – there are only so many prevention dollars –

SS: Um hm, okay.

SEAN STRUB: – that can be spent. We've already seen biomedical prevention in general — so PrEP and treatment-as-prevention stuff — gutting traditional prevention measures. And people say, oh, prevention hasn't worked. What do you mean, it hasn't worked? Against not having done it? You know? People say,

oh, condoms are a failure. Well, no, not everybody uses condoms. But condoms still are, you know, and I think should be the primary thing that we're promoting.

We make a judgment when we spend money on public-health dollars. And I think that we are spending, we are disproportionately focused on HIV prevention, in ways that aren't very effective; and not spending enough effort on broader sexual-health education. And I think that PrEP is going to make the social norm around condom use even – it'll weaken it even further.

It's weakening anyway, which is inevitable. The consequences of HIV infection are very different today. We don't have the fear driving people to condoms that we once did. But that doesn't mean we abandon them. And that doesn't mean that we opt for something that is so incredibly costly, and is rife with other potential challenges, and has not been demonstrated to be effective as a public-health intervention, at all.

SS: But condom use is not only weakening; it's out of the Zeitgeist. I mean, isn't it a stronger argument that if everybody had treatment that they need, most people would become viral-suppressed, and then there would not be transmission?

SEAN STRUB: Well, yes, certainly, that is the case. So if we dealt with stigma, in ways that are effective dealing with stigma — not bullshit, you know, bus ads and billboards and all this sort of stuff. The only way to deal with stigma effectively is to empower the stigmatized. It's a real power-transfer, quite frankly. And people don't like that. And we used to fund the networks of people with HIV. We

02:50:00 used to fund PWAC and Body Positive and Being Alive, in every city; Louisville had one, Iowa City had one. Those are almost all gone.

SS: Uh huh.

SEAN STRUB: And so if we really want to deal with stigma, we need to go back to funding those networks. That's where people learn –

SS: That's a good idea.

SEAN STRUB: – how to disclose. That's where they learn how to disclose. You used to get tested, and you were told, don't disclose, until you have created this supportive network around yourself to be able to deal with the consequences of disclosure. And here's this group; hook up with these people right here. And that's where you dealt with somebody else who was in the same situation, and that's where you learned how to disclose.

That's gone now.

You used to get pre- and post-test counseling. And then you were told, don't disclose till you have this and you connect with a network. Now you're tested routinely, you're popped out on the sidewalk, and you're expected to go home and start to disclose, or we're going to arrest you and throw you in prison.

The consequences of disclosure are far, far worse today than they were years ago.

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

SEAN STRUB: Even as the consequences of HIV infection are –

SS: Are less.

SEAN STRUB: – profoundly different.

SS: That's right.

SEAN STRUB: So we've kind of shifted it, in a way.

SS: But what is the psychology behind that? Why is Canada doing what it's doing? Why are we seeing HIV criminalization now? When the consequences, as you said, are so much less?

SEAN STRUB: Well, so we're seeing it now – I think it's a couple different things. One is that as long as we were seen as dying, very possibly a horrific death, possibly pretty soon, right — regardless of whatever moral judgment somebody might make out of homosexuality or drug use were, there was some measure of human compassion, right? Once combination therapy came out, we were no longer seen as dying. We started to be seen through the prism of our survival. We were going to be around longer, therefore we were around longer to infect people longer. So we increasingly became defined through that potential to infect, as viral vectors, as an inherent threat to society.

SS: Right.

SEAN STRUB: And at the same time, the demographics of the epidemic were changing pretty rapidly, particularly in those years, and the media coverage changed dramatically as well.

It used to be, there was a pretty steady stream of inspiring human-interest stories about some person dealing with this illness, while they're raising their kids or creating their art or doing something inspirational, and carrying on in some

admirable way. Now, when someone with HIV is written about as an individual in the media, as often as not, it's in a criminal context. An AIDS monster, an AIDS predator.

We have a whole generation – stigma – in the '80s, putting aside the issue of fear of casual contagion, which has lessened over the years, although it's still higher in the U.S. than in the UK or anywhere in Europe. But fear of casual contagion has lessened. And that's certainly a component of stigma or a manifestation of stigma. But beyond that: stigma in the '80s was principally homophobia. My little bias: the first openly HIV-positive person to run for Congress, and yes, I'm proud of that, so it was no big deal at the time. The issue was that I was gay. There was virtually no coverage of me being HIV-positive, even though I talked about it some, the *Advocate* wrote about it. No, because the public equated being gay with having AIDS. Of course he has AIDS. This was like nothing at the time.

And so the homophobia – it was homophobia; but it was from places, every gay person was accustomed to that homophobia. We knew Jerry Falwell hated us; we knew the Republicans, what they thought of us. This was not a surprise. It was like, kind of just, get in line.

Today, the stigma – whatever, that's still there; but the more-painful stigma is very close to home: it's other gay men; it's people in their own communities, where their neighbors, and their –

And I think the self-stigmatization is far worse today, because it's much more isolating to get a diagnosis today than it was years before. Years before, there was this, for gay people, and to a broad extent, people with AIDS, there was this loving

community that cared about this, and that accepted the epidemic as a collective responsibility; would wrap their arms around you, and say, we will get through this together.

That's gone. It's just gone.

SS: But I think your first two points are the strongest.

JH: Hold on a second. I have to change cards.

SS: Okay. We're almost done.

JW: I have 13, 12 minutes left.

JH: Oh you do. How did you get so much? Oh okay. That's weird because my card is empty.

JW: I'm smarter than you.

JH: I guess the cameras record at different rates.

SS: Okay. Sorry.

JH: Two seconds actually.

JW: I'm still rolling.

02:55:00 **SS: I just want to write down those two. Because you're – okay, we have to wait for the camera.**

SEAN STRUB: The criminalization, the media, the loss of networks, the loss of support for people with HIV to organize and to present their own voice and select their own leaders – the transition of a lot of AIDS activists from sort of, you know, at one time, representing people with AIDS –

SS: Right.

SEAN STRUB: – to these, you know – these centers of power, to now kind of doing the reverse –

SS: But you know, I want to float my theory.

SEAN STRUB: Okay.

SS: Do you know what the word "homonationalism" means? Have you heard that word?

SEAN STRUB: I've heard the word. Help me.

SS: Certain – okay, so there once was a time when we were all in illegality. It's like you said, gay equaled AIDS. Now, there are certain sectors and kinds of gay people who are really integrated into the power system, who have access –

SEAN STRUB: Right.

SS: – who have access to the state, and all this kind of stuff. And it divides the community –

SEAN STRUB: And who, excuse me, who, by the way, when they get diagnosed, they can keep it a secret.

SS: Yes. And they're the one –

SEAN STRUB: In the old days, on some level, you knew it was going to be public at some point. Now, you know, the Wall Street lawyer who gets diagnosed, nobody is going to know.

SS: Okay, that's one side of it. But there's also that now, if you're in Canada, and you're that person — which means being negative — you can call the police on your boyfriend, and get him arrested.

So I think that now that there are this kind of queer who is completely normative, who has access to the police, who's completely integrated; you know, the power system of some people being on top and some people being on bottom doesn't change. But who's who sometimes shifts.

So now, some queers are on top. So now we have the new queer, the new abject object. And it's the HIV-positive, the immigrant non-citizen, the person who's not in a family, are now like the bad, bad queers, and have to take that burden. Where these other people, who are in families and who are citizens and who are negative, they're the good ones.

I think that has a lot to do with this renewed anxiety about people who are HIV-positive.

SEAN STRUB: Well, and that's – I mean, that's – certainly – part of the explanation for the stigma coming from within the gay community. That's the –

SS: But also from the state. Because they've coopted a certain kind of person. It's like, if you're a gay person now, and you're not married and you don't have children; you're in a completely different position than the ones who are. Right?

SEAN STRUB: Yeah, no, absolutely. So, I've had this weird experience of learning this for the last year.

SS: Oh, you just got married a year ago?

SEAN STRUB: No, no. I've been – I'm with Paula Ettelbrick – I mean, I've always been – I've never been – I've always been marriage-reluctant as well. And Xavier and I have been together 22 years, with a little bit of a break. And a year ago, he came back from Puerto Rico, and his mother had given him this as his grandfather or something. And I'm working on my laptop in the kitchen. And he walks by, and kind of flips it at me. Says, here, you want this? And I said, you don't think I'll wear it, do you? He says, you are not going to wear a wedding ring.

So I put it on, and we're now wearing them – until we get married, then we take it off.

SS: Okay.

SEAN STRUB: Because there are legal reasons why it's useful to get married, but – so it's, and I've kept it on, because it's been a test of myself, because it's very difficult for me to wear this. I feel very defensive about it, like I have to explain it. I don't like wearing it; I really don't like wearing it. But –

JW: It creates more pain when you punch.

SEAN STRUB: Yeah, maybe. Well, but I've also had that experience of having been so – skeptical – not non-supportive, but not, you know around marriage, but then going to weddings of friends, and getting all kind of emotionally, so like, you know, having an appreciation for it there, even as I, it's contrary to – so.

SS: But anyway –

SEAN STRUB: You know, you're right. You're right. I mean –

SS: It's **a factor. I mean, you've laid out some important factors. But I also think there's some attitudinal changes.**

SEAN STRUB: Yeah. And I – I was thinking more narrowly within the epidemic. And there's also this whole thing, you know, getting into the conversations with people about – why I'm so resistant to like WHO recommendations so that everybody who's positive should go on treatment. You know, to me, this is an
03:00:00 incredible violation of patient autonomy. There is not – it is absolutely an open question whether a person with high CD4 cells will get a net benefit from treatment or not. And people are not being told this. People are testing positive, and they've got 600 CD4 cells, and they are sprinting from the clinic to the pharmacy with the prescription, in the belief that it is so urgent and important that they get on that treatment right away. And that is a violation of the Universal Declaration of Human Rights. It's a violation of the Hippocratic oath; it is – and I cannot find a single other example where prescription treatment is prescribed for people that it has not been proven that they, on average, will get a net benefit – and it's being done for a public-health purpose rather than their own individual medical benefit.

And they're not being told this. And if it wasn't for who gets AIDS –

SS: Um hm.

SEAN STRUB: – this would not be tolerated, in any other state. And there is almost no one who says this out loud, besides me and Joe Sonnabend. And it's really, really wrong.

SS: Okay, one more question on this. So the rumor is that women have a harder time controlling their viral load. Is this because these drugs were not adequately tested on women when they were developed?

SEAN STRUB: Well, certainly the drugs were not adequately tested on women; they have not been adequately tested on children. We still give the same dose to somebody who's sedentary, 400 pounds, to a marathon runner who's a hundred and forty pounds. This does not make sense. We don't all metabolize drugs the same. But it all errs on the side of giving people more drug than is necessary.

So like Viread — which is a component of Truvada — you're supposed to take every day with Viread. Now people do only when they take Truvada, but we did. When Larry Kramer got his new liver; he was taking Viread every day. They were measuring everything going into his body. So they didn't give him any more than was absolutely necessary to control his viral load.

They discovered he metabolized it so slowly that he could take Viread once a week – and maintain an undetectable viral load.

I know dozens of people who went from taking Viread daily to taking it every other day, or taking a half dose daily. It has a longer half life than a lot of these drugs. And I don't know anybody who did that who then broke through with a viral load.

But who is going to spend the money to turn a whatever it is, three-billion-dollar drug into a billion-and-a-half-dollar drug?

I think a lot of these drugs – you know, the drug development system is, how quickly can we prove a benefit without killing people, to get it approved; not, what is the least amount to give somebody to control their viral load.

I take — this, I've not written this anywhere, so here, you're getting this on camera, for what it's worth — I take less antiretroviral medication than anyone I know with HIV who is on antiretroviral medication. What I take is essentially a one-drug combination. I've been on it now four about four years. I say "essentially" because it includes a Norvir booster, but it's only a hundred milligrams of Norvir, which is not a therapeutic dose, it's just a boosting dose. And I do that with 400 milligrams of Prezista.

Now the prescription for Prezista, the recommended dosage, is either 800 or 600 milligrams, in conjunction with two other drugs. I don't take the two other drugs. I don't even take the 600 milligrams; I take 400 milligrams, and a hundred milligrams of Norvir.

SS: Now if the average civilian wanted to have your level of healthcare, what would they have to do, to have that kind of self-knowledge?

SEAN STRUB: Well, the – two things: read, a lot; and talk to a lot of people with HIV. Be immersed in the world of other people with HIV, where you can learn from this.

You know, Stephen Gendin and I could not have been more diametrically opposed in our approach to treatment. Right? Stephen wanted to try every drug. I've got a videotape of him talking in the fall of 1994, about how his

friends at TAG laugh at him that he thinks if he could take every antiretroviral on the market then, he said, a year from now, I think my CD4 count would be a lot higher. He was proposing combination therapy, before we knew it. And you read this, you get goose bumps, looking at it.

Stephen and I never argued about treatment. We were always learning from each other. It was always just so respectful, and understanding that different people will find the most appropriate course for themselves, when they're well-informed.

The problem is, like even, I have spoken to physicians who understand what I'm taking, and are kind of interested in that; but they couldn't prescribe it for their patients, because now there are these guidelines. They do this in HIV; I don't think they've done it in other infectious diseases. These guidelines create a legal liability for a doctor. So if they are prescribing off the guidelines, and somebody
03:05:00 doesn't like it, you know, or an insurer, or whatever –

SS: And the pharma does the guidelines?

SEAN STRUB: Well, essentially. I mean, they're NIH guidelines, but there are, you know, pharma people on them. And now the guideline to treat everybody is, the three standards of evidence when they make recommendations. Right? There's double-blind, placebo-controlled clinical trial. That's the gold standard. Then observational studies. Where they go and look at trials completed for some other purpose, and observe what they can learn from that. And then the weakest standard of evidence is expert opinion, right?

And so the recommendation to treat everyone is expert opinion – the weakest standard of evidence. And the experts are chosen by the NIH, and most of them have all these drug-company affila-.

You could come up with just as credible experts. I'm not talking about nutty people, or denialists. But you can come up with just as credible experts who say, no, the evidence isn't there to recommend treatment for everybody regardless of CD4 count.

There are lots of reasons why someone with a high CD4 count might choose to go on treatment. If they want to make themselves not infectious; fine, that should be their choice; god bless them. But they should know that's why they're doing it; not be misled into thinking they're doing it because the science has demonstrated it'll be helpful for them when the science has not demonstrated that yet.

SS: Right. But you were saying before – that, you know, Stephen – that people find the medication that was right for them. But he died. I mean, do you think he died because of the way he was taking medication?

SEAN STRUB: Um – I think partly.

SS: Yeah.

SEAN STRUB: But I also think there's another sort of aspect to it. I think Stephen really was a very brave and courageous experiment. He knew he was learning original knowledge about these drugs in his own body. And he knew there was a risk to that. You know. We talked about this all the time. He was about as informed – I'm not talking about somebody blindly taking –

SS: Right.

SEAN STRUB: Something from the doctor. Just as he experimented with other kinds of drugs, non-HIV drugs, as well. It was a very conscious and informed kind of choice. Sometimes I wonder, you know – because we had, you know, we had a very special relationship, that was brotherly, that was mentor, that was, you know, whatever kind of thing. And there – I mention this in the book, and sometimes I wonder: if I had pushed him harder, or been more resistant to his choices. But I've always been pretty clear about this. That's why I was so surprised when you said about me promoting PrEP, is like, James, where have you been? I mean, this is a – I'm known on three continents as the guy to talk to who's critical about PrEP, because you can't find anybody who's critical about PrEP – particularly not anybody from the activist community who has any sort of standing or stature. You – it's very difficult to –

SS: Except Larry tried, right?

SEAN STRUB: Yeah, but he doesn't –

SS: But he didn't do it in an informed way.

SEAN STRUB: –have standing on this. He's not, you know –

SS: Yeah – he was uninformed.

SEAN STRUB: – right. He did his kind of throwaway, you know, whatever sort of thing. You know, Larry –

SS: Did you think that poisoned the waters for a good –

SEAN STRUB: It didn't help.

SS: Yeah.

SEAN STRUB: You know, Michael Weinstein's comment about it being a party drug; you know, that doesn't help, either. Even though a lot of what AIDS Healthcare Foundation has said around this is correct. And people make the, they don't understand the difference between something being appropriate for an individual to make as a decision; and for a doctor to say, you know what? James, you know, you've been my patient for awhile. I know you, and your challenges, and your whatever. And I think maybe this is something that you should think about, that's appropriate for you.

Great! That's fine.

But that's very different from making a blanket recommendation to physicians to recommend this, or advise their patients of this, not taking into account those individual circumstances. And we're moving towards an increasingly kind of cookie-cutter medicine. Doctors are coming out of med schools, and they're pill dispensers. Their discretion has been narrowed dramatically – legally, and the educational system, and pharma funding the curriculum at the schools, and everything else.

So while we know PrEP works at preventing HIV, for the people who take it — there's no question about that; you're not going to get HIV if you take PrEP; if you take PrEP properly — there is no evidence that it will work as a public-health intervention.

SS: Right.

SEAN STRUB: And there are lots of things that can work as an individual decision that don't work as a public-health intervention.

SS: Okay: final question. What do you feel about antibody-based vaccine?

SEAN STRUB: I don't know anything about it.

SS: So vaccine is not on your radar.

SEAN STRUB: You know, I read stuff about it occasionally, but I'm not informed enough – I'm still stuck on Margaret Heckler in April of 1984, we'll have a vaccine in two years.

SS: That's right!

SEAN STRUB: Um –

SS: Right.

SEAN STRUB: Uh – so, you know. I mean, I'm delighted the work is underway, but I can't speak about it.

03:10:00 **SS: All right, thanks a lot, Sean. It**'s **been great. Thank you very much.**

SEAN STRUB: You're welcome.

SS: We'll unplug you. That was a long one. Thanks for your stamina.

JW: And thanks for the clarification. Glad I – glad I provoked it.

SEAN STRUB: Well, well, it's because I take so much grief about it. You wouldn't –

JAMES WENTZY: Huh?

SEAN STRUB: – believe the abuse and the grief for anybody who says this kind of stuff. I mean, it is – uh – and on the treating of the high CD4 cells; the only other person I know who is out there who will say this stuff is Gregg Gonzalves. And we're actually on a discussion on a Listserv right now, and when he chimed in, I felt like the cavalry had arrived.

SS: Because Peter [Staley] is gung-ho-ho-ho pro, pro, pro.

JW: Because David France is a pill for everyone.

JH: Well I did a screening up at Albert Einstein about a year and a half ago, I think. Maybe it wasn't that long ago, but anyway, one of the doctors after the film started talking to me about that. And said he's very uncomfortable prescribing medicines –

SEAN STRUB: This is what you find when I'm out and I've done 65 or 70 events around my book this year so every time the conversation ends up becoming about PrEP and Treatment as Prevention. Out there there's very little support for this and a lot of real concern. The informed people at the service providers, they all understand who should be getting PrEP.

JH: No, no. I meant about starting treatment early.

SEAN STRUB: Starting treatment – there's broader support for that because they're all poisoned by the public health perspective. They just, they think they know better and they need to virally neutralize all these people and spray them with Raid so they don't spread it to anybody. But public health is becoming militarized

as well. It isn't just the police. Public health is and very often working in concert with the police like in Michigan now. I think they're a prosecutorial prospecting system for the cops.

JW: If you live in a state like that, how can you advise someone to get tested?

SEAN STRUB: Yeah. Yeah.

JW: Shouldn't the CDC re-think that prevention campaign "Know Your Status," come out against criminalization?

SS: They don't care.

SEAN STRUB: Listen, Thomas Frieden, I think, in his heart of hearts totally supports criminalization. When he was still in New York City, I had a meeting with him – the one time I've ever met him with another person – and it's when they were developing the "It's Not Just HIV" campaign. Did you ever see that video?

SS: No

SEAN STRUB: It's horrific. It's not just HIV, it's anal cancer and they show a picture of a lesion on someone's ass and it's osteoporosis and they show x-rays of bones breaking. And of course all of those things can happen, but then they have these cute boys who look like they're from "Lost" or something looking mournful. And then at the end, it says use a condom every time. Larry [Kramer] loves this. You look at the research for this kind of stuff. People who are already engaged in the desired behavior like the ads. It's an endorsement of how smart they are. The people whose behavior you're trying to change, it pushes them further and further away. It's

like in 5th grade when the cop came in and held up a maryjane cigarette and left you terrified that if you ever smoked one of those, two weeks later you'd be slamming heroin, right? At a certain point you learn that's not true. That it's this big lie. And that's what we're doing with HIV.