

**A C T U P**  
**ORAL HISTORY**  
**P R O J E C T**

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**MIX – THE NEW YORK LESBIAN &  
GAY EXPERIMENTAL FILM FESTIVAL**

Interviewee: **Joseph Sonnabend**

Interview Number: **187**

Interviewer: **Sarah Schulman**

Date of Interview: **November 12, 2015**

**Part I**

**SARAH SCHULMAN:** This will be the final interview in the ACT UP Oral History Project.

JS: Hm. Really.

**SS: Number 189<sup>1</sup> that I've conducted over 15 years. And I'm very honored that it is with you.**

JS: Oh, thank you.

**SS: So thank you so much. So the way we usually start out is you say your name, your age, today's date, and where we are.**

JS: Oh, okay. That's how we begin? All right. I'm Joseph Sonnabend, and I am 82 years old. And we are in my apartment in London. And today is the 12th, I believe, the 12th of November, 19-, no no, 2015.

**SS: Okay, great. Thank you. So you grew up –**

**SOULEYMAN MESSALTI: So if we just move the back end, here in the background.**

JS: I talk rather softly. So I hope you don't –

**SS: It's in the mic. It's – do you don't – Are you listening on the –**

**SM: Yes.**

JS: I've been told I speak too softly.

**SS: So you grew up in South Africa.**

JS: I grew up in what's now Zimbabwe, actually, which was Rhodesia then.

**SS: And how did your family get there?**

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<sup>1</sup> There have been 186 interviews with 188 individuals since 2002. They are numbered 2 – 187.

JS: I'm not entirely sure of the details. They got there – I believe it would have been about 1930. And they got there under the auspices of an Italian expedition. My father was a sociologist, working in Italy – had studied there as well. My mother, not a sociologist, but she also had been a student, a medical student. She was a physician in Italy. And my father came out on – it was an Italian expedition to study – well, the book when it or the report which was a book, it was entitled “Some Aspects of Private Organization Amongst Bantus” [*Il fattore demografico nell'organizzazione sociale dei Bantù*] that involved maybe three or four years of my father doing a social-anthropological something in the – I suppose in northern South Africa, in what's now Botswana – I think, as much I know those things.

But of course, they were Jewish, and I don't know the circumstances. I rather think my father's — and in fact, this is sort of going on now a little bit. I may even discover some answer to this — but I rather think that my father's patron was a man called [Corrado] Gini, who was a rather eminent sociologist, interested in movements of populations, which was my father's thing. But he had a warm relationship with this man. And I rather think this Gini, who was an adviser – he was a theoretical apologist for Fascism. These things are a little bit complicated, but he was a pretty eminent man — and I rather think — now I don't know this to be the case — that in 1929 or thereabouts, I believe that race laws were being put into place in Italy, following the German thing, so a Jew — I mean, my father — would not have been able to continue to work, continue to work at an Italian university where he had been working. And I think his boss, Gini, kind of organized to save him, rescue him, and sent him to Africa – managed to find a framework in which my father could leave.

So this is not quite the usual Jewish immigrant story, but sort of connected, in a way. And I know that my father came in that particular framework to work in the field, as it were. But the circumstances that led to this, of course I don't know. But maybe I'll find – it turns out my father left an archive, which somebody is going to try and find. It happens to be in Jerusalem, which makes it a bit inconvenient at the moment, but, heh – I may actually finally get some information about the circumstances –

**SS: So your parents were Italian?**

JS: No.

**SS: Ah.**

JS: No, they were just ordinary Jews. By this, I mean Middle European, Russian.

You know, more –

**SS: So –**

00:05:00

JS: – more understandable, yeah. There are Italian Jews, not too many of them.

**SS: No. But so your parents were Russian.**

JS: No. My mother was – grew up in Russia. She was born in Lithuania, but her childhood was spent in – I do know. I'm not somebody who runs to try and do family roots, or anything. I'm not uninterested, but I'm not dedicated, as some people are. And so I'm – I've read enough stories, so I could interchangeably be one of the, one of them, I don't need a detailed story of my father's or my mother's family saving themselves from the pogrom, and going here and going there, one of those stories. Not to minimize it.

But bits and pieces I do know. My mother and her sister were born in Lithuania, but they were sent to relatives in a place – which is actually in the Soviet Union now, but – well, it was – not in the Soviet Union. It's in Russia, not Ukraine, because it was close

that much I do know. And it's called Belgorod, where they grew up, and my mother and her sister then became medical students in Leningrad, in about 1918 or so. And in the early 1920s, I know that they left. Now the circumstances of them leaving, I don't know, or how they managed, the two sisters, to go. And they found their way to an Italian university, in Padua, where they completed their medical studies.

And so, a little bit I know about that is that in those years, 19—, Mussolini had been trying to make his universities, I had discovered these things along the way, make his universities attractive to foreigners. So I have over the years encountered other people from other parts of the world who, in those years, went to Italian universities.

And so my mother then became a medical student at a Padua university, as did her sister. And my father happened to arrive there with a, from Germany. My father was – I can't even say "Germany" – he was born – I can't even find it on the map, by the accounts of whatever papers come my way, and it's all haphazard. It was a town in East Prussia, which became – when he was born, but of course it became, I think, Russia, then Poland. It went through – you know, so who knows, I mean, who cares anyway, in a sense –

**SS: So it's like Austro-Hungarian, something –**

JS: No, not Austro, but – Prussian, Polish, Russian; after the first war, I think –

**SS: But it's remarkable that they were both university-educated –**

JS: Why, why?

**SS: – considering their backgrounds.**

JS: Why?

**SS: Because most Eastern European Jews, especially from Russia and Lithuania –**

JS: Hm.

**SS: – had been denied access. So your –**

JS: Well, this is not quite like that. You see, my mother was of an age to go to the university when the Soviet Union existed.

**SS: Right. So she benefitted.**

JS: That's right. So that didn't apply, you know. And in fact, she did begin her studies — I've got bits of photographs and things, so I do know that — in — when did Leningrad become Leningrad? I suppose in 1918, those years. And that would have been about right. I probably could find, by looking at the photographs and the dates. I've got student pictures from Leningrad with my mother in them. And they probably have a date on them. Just odds and ends found their way to me, over with the family's disruption –

**SS: So how did they – what was their existence like in segregated – in apartheid Rhodesia? I mean, how did they adjust to this?**

JS: Well, I don't think they understood much. Or you know, one has to put oneself back – I don't know, but I'm assuming — that one, first of all, has to put oneself into the cultural kind of attitudes of much as we can recreate them that existed in the 1930s, which are not at all what they are today. So we shouldn't bring our contemporary yardsticks, as it were, to judge another time. And I can't say exactly what they were. But yeah, I've asked myself, was it, how do people from that – sort of educated Europeans coming to such a strange society, and how do they – I know it's a puzzlement, but I'm

sure it's complex, you know. Because it's not as if they from simple – they also knew discrimination, they knew all sorts of different things. Across Russia, Lithuania, Germany, Italy, Fascism; it wasn't as if they were strangers to, what you might say, odd circumstances. So –

**SS: Well, what about for you, when you were growing up?**

00:10:00

JS: Well I was born there, so I –

**SS: Right.**

JS: – grew up indoctrinated, I suppose, as anybody else would. What do you want from a newborn, you know? It's –

**SS: Right.**

JS: And so – yeah, that's how they came there. No, not quite like that. Well, it was Rhodesia. My mother had an Italian and her sister was not married, a whole bunch of them arrived. My father had to do his job, as it were. He continued to do his. It took him maybe four years, or something. And there wasn't a question of going back to Europe. By now, we're in the 1930s, and – my mother went to Rhodesia, for the reason that Rhodesia was a British colony; and the Italian medical degree, there was a reciprocal arrangement with Italy, so she could practice, and her sister could practice, in Rhodesia. Not in South Africa; it didn't have that arrangement.

And then so my mother and her sister started a medical practice, I suppose right about 1931. And they were quite adventurous for women, in those years. I believe they were the first women doctors in, well, what was then a colony. And my father finished whatever he had to do he – the only place he could go to was a university environment. So he became part of the sociology department in the university in Johannesburg, where I

ended up myself. And so he, for those years until the war began, he was a faculty member at the university in Johannesburg. My mother lived in Rhodesia – it was only about 800 miles away. Well, it didn't seem like all that much in those, you know, given the way the country was – rather spread out, and large distances, like America in a way, with not very good roads.

**SS: So you were at the University of Johannesburg.**

JS: I ended up there yes.

**SS: Were you aware of yourself as a gay man at that point?**

JS: I don't think the terminology existed. I was aware of myself as kind of rather sexually interested in young men – didn't have much in the way of – it's a different age. I grew up in a boys' school where everybody was having sex with everybody. So it wasn't – this sort of notion of a gay identity, I can't say existed. I don't think so. I didn't give it much thought, to tell you the truth. But – yeah.

**SS: So at what point – and you went for medicine.**

JS: I went for medicine. Well, it's a little bit complicated. Do you need to know all these things?

**SS: Yes!**

JS: It's interesting, but it's –

**SS: Because it helps us understand who you became.**

JS: Oh. Well, okay. My father – the war came, and my father was pretty much involved in the war; first as an official, a welfare officer to a huge Italian prisoner-of-war camp in South Africa; which is the suburbs – this is coming back to me, because there are survivors, or the families of survivors of this camp. And my father, who became the

welfare officer for this is for the prisoners, had really probably more in common with the Italian prisoners than with his fellow officers in the South African army. And so he did that – became a very unusual camp, this called Zonderwater, which only in the last year has been the subject of some interest in our – it's kind of strange that at this part of my life, that I'm discovering odds and ends about my father.

But it turns out that this camp in Zonderwater was a — called Zonderwater — was a model that, in the sense that the facilities, the schools were built – theatres, musical instruments made. It was quite a remarkable place – I didn't quite realize how just remarkable until rather recently. And the reason for that is I have an Italian friend who is a lawyer, in Turin. But he's a lawyer involved with human rights issues – not a practicing lawyer, that sort. And so he has colleagues involved with the legal aspects of war. It sounds a little gruesome, but there are such things. And in fact, there's somebody here in London, an American woman – she's Canadian – who's been involved with, anyway.

00:15:00 What I've discovered is that this camp, this Zonderwater, has been known in those people interested in prison-of-war camps, as a remarkable place, because of the facilities that were produced and the sensitivity. There were 70,000 prisoners in the camp. And I have tons of things – my childhood I remember for example there were artisans, produced furniture. I mean, I think even around here, there's probably objects that were made for my father. There were artists who were encouraged – sculptors, painters. I've got paintings all around here I can show. There are still stuff that remain here that I still have, that came from those camps, anyway.

This year, there was some – the families of the prisoners have an association, in Italy near Buca. And they asked me to go to it — I didn't go — an annual, but this time was sort of special thing. And they put on a set of, whatever – an anniversary event. And through this lawyer, I sent things, as much as I could find; writings of my father's, around those things. And as it turns out, this is what I discovered: as it turns out, nobody really questioned how this camp became what it was. And they assumed it followed the Geneva Convention. So I discovered it also through this – Heidi, her name is, who's at SOAS [School of Oriental and African Studies, University of London] here, but her specialty, she's a lawyer from Cambridge, who is a specialist in war. I mean, there are people who look at war treaties, the Geneva conventions, in an academic kind of way. And so – and she is now spending six months or something at SOAS.

So I had discovered that, no, the Geneva Convention contains things, but the Geneva Convention apparently, it originates in 1929, something like that. And it was reformulated in 1949 – that's after the war. And in the course of reformulating the Geneva Convention, people from the camp, my father was among them, were a part of that; and so not that the camp followed the more recent Geneva convention, but the Geneva convention followed this camp.

So anyway, somebody's writing about it. Which my father apparently had a lot to do with. And undoubtedly because he was a culturally, sort of an Italian – that was his – I mean, he was German, German-speaking, but his academic kind of bias, as it were, was an Italian one, and he certainly identified I suppose as Italian.

Anyways, there's that part. The second part about the war was, of course, since he was Italian-speaking, German-speaking, he was sent to the war, to Italy. And he was

attached to the Fifth American Army. He'd never been to America, but he was actually part of this American army. And the reason was that they ran something called the Psychological Warfare Branch. And part of their job was, as the army advanced and liberated — you can't say "occupied," liberated — or, liberated from the Fascists, and you know — towns and cities, as they were moving northwards, one of the jobs that needed to be done was the reorientation of the press, of the newspapers, and they had to change it from a pro-Fascist to a pro-Allied editorial response, you know. And so that was my father's job. Not just him, he was part of the unit, that when they came into a town, they had to find, they had to start producing newspapers that were of a different editorial policy.

So there were lots of things then that — that part I became somewhat aware of myself, because I was old enough, at this point. So now back to my father.

During the war, he was away from, obviously, his university job. And I think he actually enjoyed — you know, he really had a, he threw himself into this. He was a very observant guy, enormously well-read. He prided himself on never reading fiction — I never understood why — but it was actually a point of pride, that he would boast about. He had a huge library, and he was kind of an observer, you know, he enjoyed looking at things, and coming up with what he thought were smart observations. And maybe sometimes they were.

Any rate, after the war, he returned. And at that time, the chairman of the department of sociology, who was — this is just another little aside — his name was John Gray, he was a British sociologist, who'd come to be chairman of that department — my father was the next-most-senior person in the department — and John Gray was married,

had two daughters. And I'm sure, Simon, you know this one, I've told you this one, this story, I'm sure I have — and he — I suppose this might have been 1947, or '48; just shortly after the war, my father had just returned. So this John Gray had a sabbatical, and he sent his wife and two children here. And he followed — on a ship — in those days, that's how you traveled; I too remembered, when he took two weeks from Cape Town to Southampton — something I did a few times in those years.

So John Gray traveled in a cargo ship, with one of his male students. And this ship caught fire off the coast of West Africa, and sank. And poor John Gray drowned, but the student lived to tell the tale. So this was the sort of the scandal of the time.

So quite strangely, then, my father became the acting head of the department, and — it was in 1948, because that was a momentous year in South Africa. It's when the Nationalist Party, the apartheid party, took over the government, and started really turning the screws on segregation, in a bad way. And a lot of people left, including my father.

So he left, my father left South Africa, as many — he wasn't the only one. It was not a happy time in South Africa. It was the beginning of, really, the worst of the apartheid years. Not that the British were a whole lot better, or the other side, you know. Rhodesia never had apartheid segregation laws, but it was every bit as segregated as South Africa then.

Any rate, my father left. But I found — I was then 16, I suppose. I was a kid, you know. And my father had — my mother had died shortly, and my father remarried. And I — was left with my stepmother in Johannesburg. And my father moved — he ended up in Geneva, but I had to clean out his, sent his books and his office. I was left with the task

of ordering in the movers to pack up his library, with thousands of books, from his university office. But I found – the bookshelf went to the top. And there was about this much space between the ceiling and the top. And a ladder – I found a shoebox. This used to be the office of Gray, John Gray, you know, my father, for the years he was acting head – he had moved into that office.

And I found this shoebox. And it was really – and I was 16 years old, and – in the shoebox, there were all the sort of love letters he'd received from his wife. There were things to do with men he'd been involved with. There was a packet of condoms, which I opened, all just turned into, shhh-, dust, you know, they'd been so old. There were letters from people like H.G. Wells; all sorts of eminent people. There was also a speech of Bertrand Russell, written out in his own hand.

And I thought, what am I going to do with these things? I didn't know what to do.

**SS: Wow.**

JS: A strange little thing. Even I was aware of it, as a 16-year-old kid who finds this. And of course I knew the names; I was reasonably educated.

So years later, when I was already living in New York; I wondered, I used to come back quite often; my sister lived here. And I asked her once if she remembered what – I didn't remember what I did with this box, and I thought, well, maybe we can sell, there might be – maybe hang one, there's a speech, but I remembered those things. And it seems that she had got ahold of it, and she'd just breezily said, oh, I sold those years ago.

**SS: Hmm.**

00:25:00

JS: So that was that. Anyway, so my father ended up in Geneva. I went to Geneva — I was 16, 17 — I went to Geneva myself, to be with him. I was approaching the years when I was supposed to decide on a career, you know. I didn't know what I wanted to do with my life. The idea of medicine sort of was a huge turn-off. I think from the experience of growing up in a house — there were no men in the house; I was the only man in my mother's house. And my mother — it was my mother, her sister, unmarried; both doctors; and my sister, who was younger, two years younger than I; and me. I was the man of the house, as a kid, you know.

And so I think just the expense of a doctor's life — a general GP; both my mother and her sister, they both had cars, they both did home visits in the middle of the night. I had all these memories of the phones ringing at three in the morning, and one or the other of them going out to see a patient. And somehow — I was quite opposed to the idea of being a doctor.

And here I'm in, now in Geneva. The academic year is beginning. And my father was a totally open-minded kind of guy. And he said, well, you know, make up your mind, what do you want to do? And he didn't influence me one way or another, except for getting a little bit irritated, because, you know, you've got to get on with it. And I thought, well, should I be an architect? I even thought about — but I had no enthusiasm for anything. And I think just maybe because of the pressure of the approaching academic year, I quite suddenly decided to be a doctor. It was just like that, you know. And maybe — but I was quite in — having made the decision, I was quite turned on to the idea.

And so I did start my medical studies in Geneva. But in those years, the Swiss degree wasn't recognized in the English-speaking world; but the South African degree was. And so, having my father having been connected with the university, I don't know what happened, but it was – without problems, I had a place in the university. I went back to South Africa to become a medical student. And the moment I got my degree, I was out of there.

I had an incredibly good education. In fact, I'm very pleased that that happened at that time. It was an incredibly good medical education.

But it was insufferable. I had no idea of living in that particular, so –

**SS: What year did you come to New York?**

JS: Oh – I came to New York in 19...the first time would be about '67.

**SS: And did you have a lot of gay patients in your practice from the beginning?**

JS: No, I didn't have a practice in the beginning. I wasn't a doctor.

**SS: What were you doing?**

JS: I was an academic doctor. I worked in medical centers, did research.

**SS: Oh, okay.**

JS: I was a research doctor. I had quite a long career in research before – it was only an accident that made me a doctor-doctor.

**SS: What was the accident?**

JS: Well, a bad departmental chairman, I suppose, was the accident. It was an accident. No, I had no experience as – I mean, I worked for years, even in research labs. I worked for the Medical Research Council here they're the largest now in Mill Hill here

in London, and – I worked for the man who discovered interferon. That was my particular interest –

**SS: You worked for the man who discovered interferon.**

JS: Yeah, yeah. And –

**SS: Okay.**

JS: So I know a lot about interferon, and no one seemed to want my knowledge.

**SS: Let me ask you a question about interferon, before we get back to New York. So interferon was originally designed as a cancer drug, right?**

JS: No.

**SS: No.**

JS: No.

**SS: What was its first intention?**

JS: It wasn't a drug; interferon wasn't discovered as a drug; interferon was discovered – here – in the room where I ended up working myself, a few years before I arrived there. There is such a thing called viral interference. It's a phenomenon that has been studied for as long as virology as a discipline has existed, and that's well before we could do tissue-culture stuff. And so one worked with mice, with animals, and things like. But viral interference is a phenomenon where you, if you infect cells or an animal with a particular virus — say an influenza virus — then you try and infect them with another virus — not influenza — and it was observed that there's a period when you can't do that; that the animals who are already infected with, say, influenza virus, become immune to certain other viruses, apparently unrelated.

00:30:00

So that was a phenomenon for viral interference, which interested many microbiologists, including Alick [Isaacs], my boss. And his discovery was – well, there are many, as it turns out, in reality, there are many mechanisms that can explain the phenomenon of viral interference – it’s not just a single thing. But his contribution was that he found that interference — the phenomenon of conferring resistance to superinfection with unrelated viruses — could be mediated by a non-viral molecule or molecules. So that could be recovered from people infected with a virus.

In other words – the way he did this was in eggs, in those days. He infected an egg with influenza virus, say; and then he removed fluid from the infected egg, say two or three days later — this is exactly what he did — and then made sure that that fluid contained no virus — it didn’t contain any virus at all; and if he exposed other eggs to this fluid. And then he found that it was impossible to infect these other eggs with –

**SS: Oh, wow.**

JS: So the phenomenon of viral interferon could be transferred by something in this fluid. And he called this something “interferon.”

Well, he really, in those days — it was 1957 — in those days, I suppose, he made a big leap, to say that in this fluid, which is full of things, that there is a unique molecule that confers this resistance. And he decided to call it interferon, which was maybe his most imaginative leap, because the name sort of had a zing to it, and really, probably, the name itself probably did more than anything else.

Well of course, he was not – he wasn’t entitled to it, he didn’t have enough information to attribute interference to a unique molecule. It could have been — and in fact, it probably is true — in that fluid, there were lots of things that mediated interferon.

And in fact, as it turns out, the interferon itself, there is such a thing as interferon, but it's not one thing. Numbers – lots and lots of interferons. And so you had interferon A, B, C. And there's other – all subtypes. But nonetheless this idea of saying, it is a unique substance did a lot to – interferon is now the future. Well, can we use interferon to protect people from viruses, because if we can do this in eggs, well maybe we – you know, this is just crude fluid; how do you get this interferon, if there were a unique one; how do you get it out?

Anyway, that's – interferon was discovered as an activity, one should say, rather than a molecule. Of course, the activity resides in a series of molecules. But interferon's, interference is mediated by interferon – it is an activity. And this became of great interest, because there's a potential for an antiviral drug.

And so this was 1957. And of course, it took centuries before that could be actually turned into anything practical. And along the way, there were all sorts of other things discovered about interferon that – for example, that it has many effects in the organism — interferons — including effects on endocrines, immunological functions.

Alick had the idea that it could be used against cancer. And that's an interesting story, how he came by that idea. But poor Alick was – he was a man who we'd call bipolar today, I suppose. And I actually ended up looking after him, as he became — he died — but he became kind of psychotic, and he had these ideas about cancer – well, it's hard to explain, but he had a notion that interferon could protect organisms against foreign nucleic acid. Which was a silly idea, and it was – well, it was based on – antibodies – immunologists, in a sense, that the immune response is a response to foreign proteins. Which it is. I mean, when you get exposed to a bug or something, your

immune response, your antibodies, your T-cells, are recruited in order to get rid of a foreign protein. But he tried to make the same analogy with nucleic acids, and he thought cancer was foreign, that you had mutations in the cell, and that interferon could –

00:35:00 The reasoning was all – was not right. But in a way things are, he was right. In most – unfortunately, he died. But he was actually right. I mean, conceptually, he was right. Of course, we know much more now about how interferon works. And you could say, I have a certain pride, I suppose, is that the team that I was involved with, and that I arrived at Mill Hill with; he discovered interferon – in the days of old-fashioned microbiology. There was no molecular biology. And the later – sort of growing up in the early 1960s. And I started, I'm not trained, as many of us, to try and use molecular biological techniques to study interferon here.

And so this team that I was part of, a few of us, continued, and we moved from the virology division, where I was, into the biochemistry – because it became that way. And in fact, the team that ended up discovering how, essentially, interferon works is the pedigree, you know, it's my people, in way. So I'm kind of happy about that.

They've moved away from Mill Hill to other places. And what makes it even more interesting is that the mechanism that worked for interferon, that we worked out through interferon, turned out to work for all cytokines. So something very fundamental was discovered about the interferon system that affects all cytokines. Interferon was the first cytokine, but we didn't have the name then.

And then the people who were involved were people who are descendants of Lee, you know, the team that I was involved essentially. I'm very happy about that.

So interferon was not a cancer – it was a notion, in fact, that’s how I met Mathilde; through all of this; in – shall I tell you? If don’t know if I should.

**SS: Well – what year did you meet her? Just tell me the year.**

JS: I first met Mathilde in Israel, actually, in the 1960s. But I can’t remember much.

**SS: Okay.**

JS: And there was a fellow called Emmanuel [Heller], an Israeli virologist, who had been at Mill Hill when I was there. He was a visiting scientist. And so we became friends then. And then he went back to Israel. And Mathilde worked at the Weizmann Institute in those years, in the 1960s.

**SS: Oh, was she a refugee?**

JS: No. Mathilde, was not a refugee at all.

**SS: Why was she at the Weizmann?**

JS: She was a terrorist. I mean, I’m joking, a terrorist. She would say so herself. Mathilde married – her husband, in those years, was a gun-runner. He used to –

**SS: For the Irgun –**

JS: Yes! So Mathilde used to go and bring guns from – I don’t – she was involved in – she married him, and she became Jewish – speaks Hebrew – and she was dedicated to this –

**SS: But she was German.**

JS: Swiss.

**SS: Swiss. And what was her husband’s name?**

JS: Oh, I've forgotten now. [David Danon] It's – god – it was quite well-known – it was quite a well-known – you can say, in those days – the rules were different then.

**SS: I understand.**

JS: The Arabs, another world. So he was – the current freedom fighters – in 19-, whatever it was, 1948 – anyway – just after the war, you know. And yes – that's how she came to go there, and settled there. And then became a scientist, a geneticist, worked at the Weizmann Institute. And Manny knew her. So on a visit to Manny myself, in the 1960s. But I can't remember that, really. I can't remember. But then later on, in 1971 – Manny, my friend, the Israeli fellow, was again in New York.

**SS: Was that your partner?**

JS: Partner?

**SS: Boyfriend?**

JS: No. Manny was a – well –

**SS: A science –**

JS: He's a scientist. Manny was a friend, you know. A scientist friend. His wife is an Italian Jew. There's an example of an Italian Jew. His wife, Michelle, is a painter, artisan. I don't know what's happened to her. She was – a strange thing, an Italian Jew. There are such things.

**SS: Yeah, of course.**

JS: And so she was one of them. So in 1971, Manny was in New York, for whatever reasons. And Mathilde was an old buddy. By now, Mathilde has married Arthur Krim, so now she's just a big socialite, a different world. She's now translated

into – whatever – working at Sloan Kettering, and all of that kind of stuff, you know. A socialite – entertaining presidents, whatever, in her grand house.

00:40:00 And there had been a report that a Swedish — Hans Strander, his name — a Swedish scientist — had treated people with a bone tumor called osteogenic sarcoma, which is quite fatal, a horrible disease — had treated them with interferon; and a whole lot of them recovered, or their cancer — this was big, hot news, you know, sort of amazing, interferon. And so Mathilde, being Mathilde, being — she is an old friend, you know, and I have a huge kind of, a lot of history with Mathilde — nothing to do with AIDS, even; long history before AIDS. Anyway.

She decided she wanted to promote interferon. I mean, this is all, you know, Hollywood. So it's a different way of doing science now, so nowhere in the public, anyway. A whole other kind of world; not the one that I grew up in. And so she wanted to break into the interferon — wanted to be a personage in — and she was a real scientist; but nothing to do with interferon. And so she asked Manny, an old friend of hers, who was an interferon scientist; and then Manny suggested she meet me, because I knew everybody. The interferon world had been small. And I would say that when I was in it, with Alick, in the early years, in the early '60s, I knew everybody. There were a handful of labs in America, a few in Europe. It was a small world, we all knew each other. And now it's still a small world, but not that small, by 1971.

So the way that Mathilde broke into the field was by sponsoring a meeting at the Rockefeller University, which was to do with interferon and cancer, because these results were in the air. So she — Arthur, the Krim Foundation, I presume — together with the

Cancer Institute, sponsored a two-day symposium at the Rockefeller, in 1971, '72, I can't remember.

Well, Mathilde didn't know anybody in interferon, so we became sort of – you know, I was quite enthusiastic. It was a great idea, you know, and she said, here's my phone, call the world. And I'd make calls to Australia, to Israel; god knows, to fellow scientists, you know, and so forth. And so we had an enormously good time, not a good time – we had this meeting. And I gave the keynote, one of the keynotes, as I was the descendant of the discoverer. Still got those things.

So I had a, well, huge life before this epidemic. And, um – a better one, too.

And so then I had my first big falling out with Mathilde. Really major, major falling out.

It turns out that Mathilde wanted to establish a lab at Memorial Sloan Kettering devoted to interferon. She has no background in interferon, but she – this was her ambition, to set up a lab.

It's okay; you know, there's nothing wrong with that. I mean, you can sponsor it, and you get the right people, and all of this, and you can do something good.

**SS: Good.**

JS: But she was being besieged by eager young men who knew about this, and tried to get to her through me, and said, who saw an opportunity for themselves. And they're not necessarily the best people.

But I knew this. Here am I, you know, and I'm trying to protect her effort. And she asked me — so this is the first time, I knew about – during – so the meeting happened. And it was really — I've got some photos of it — it was really a wonderful –

interferon had been lagging, in those days. I mean, funding had sort of gone; the idea of using it as a drug for virus infections hadn't panned out. So it was huge disappointments. And it was languishing, none of us – A mechanism of action hadn't been worked out yet. The purification, which I had been involved with, had not succeeded.

And this was a shot in the arm for all of us. We all kind of felt a new light. A cancer – you know, money, cancer, excitement, whatever – you know, quite genuine excitement, as well.

But as far as the cancer thing, I should say, before long, it turned out to be – nonsense. It turns out those osteogenic sarcomas were not osteogenic sarcomas. Big scandal. Other people reviewed the slides. So they were things that you get better from anyway, so –

**SS: Oh.**

JS: But it turns out that actually, there is a cancer connection. Not that, but just the fact that people got working, and interested in it, and the fact that interferon studies had now included interferon's effects on immune functioning. So – there were mechanisms that were becoming – it was really – quite exciting. So the initial premise turned to be a bust. But, like many things, the importance of an idea isn't that the idea is right, but it gets you moving. And in the course of movement, something really good comes about. That's an old thing –

00:45:00

**SS: Right.**

JS: – I think that's how the world often does work. The importance of an idea –  
{PHONE RINGS} Would you, Simon [Watney]? I don't want to –

**SS: So.**

JS: Forgive me.

**SS: Let's just wait till he –**

JS: Maybe I have to deal with it.

**SS: Alright, let's just wait one minute –**

JS: Forgive me. I've just had a bad thing happen. My sister just died a few days ago.

**SS: Oh, okay. I'm very sorry to hear that.**

JS: What can I do?

**SS: That's terrible.**

JS: Well she had a very good life so anyway. So now it does mean I have to deal with things.

**SS: Right. Let's find out what that is and then let's move into the –**

JS: I hope it's – I've got to do the thing.

**SM: Do you mind if I move that chair behind you? Move it here.**

JS: What do you want?

**SM: I'm just going to move that chair.**

JS: Whatever you like. You want me to move, I'll move. But it does mean that I have to deal with things. Should I bury her or cremate her, what do you think?

**SS: I would say cremate her.**

JS: I'm sort of leaning that way. But it's cheaper, and I don't want people to think I'm doing it because it's cheaper.

**SS: No. I mean, was she religious?**

JS: No. Not the slightest bit.

**SS: Then – it's better for the Earth.**

JS: Anything I need to do?

SIMON WATNEY: It was Michael Schenk.

JS: Who?

SW: Michael Schenk. Yeah, okay.

**SS: Okay, so I'd like to move now into the AIDS era. That's very good background – it will all come back.**

JS: – lots of other things – I had a big falling out – that's important for the AIDS thing – to hear about the falling out.

**SS: Okay.**

JS: – because it's the coming together that brought – the falling out had to do with the fact that Mathilde said, told me then, I'm thinking of doing a lab now, and I need to hire people, so would I, me, help you.

So I – I had buddies all over the place, in this. And I did ask them. And she said, don't tell anybody. And well, it's kind of hard to help recruit potential scientists for what's going to be a big lab, and she was looking for funding for that, and she succeeded in getting it, with keeping a secret. But I did my best, you know. I asked my people – at that point – I was pretty advanced myself, I mean, in the sense of my career. I'd been associate professor for a good number of years, at that point. And, in fact, when AIDS eventually came about – for the previous eight years, I'd been associate professor, first in microbiology at the Mt. Sinai School of Medicine; then I was associate professor of medicine at Downstate [SUNY Downstate Medical Center] for – how many years. And so I was – I had my buddies in the same thing, and I asked them.

And then one day, I was in Mathilde's limousine sitting in the back there and she threw me out of her car.

**SS: Oh.**

JS: And she got very upset. She told me she received a letter from somebody at NIH, saying, I hear that you are starting a lab. And if I can be of any help to you, I'm quite excited, you know. Just let me know, I have some suggestions for you. And at bottom, it said, copy, Dr. Sonnabend – I was at Downstate then.

And I told you not to tell anybody, uh-rah-rah. She threw me out. And then I still tried to help her. I thought the people chasing her were, some of them I knew them not to be terribly good. They were just ambitious. And I still tried to help her. And I did suggest to her that – she had an advisory committee for the lab. And I told her, you know, if you bomb, you can always paint the advisory committee – it was, tried to, you really respect and I knew the top people in the field, and I spoke to them. And four or so of them agreed. I mean, really, the most – I knew them all. And they agreed to do this. And she treated them like shit, you know, and didn't – she didn't – she made a big mistake.

And of course, the person she hired to run her lab – I'll stop when I tell you how – she got into AIDS. Because it's related to this story.

**SS: Okay, all right.**

JS: And then you ask me, you'd better ask me, because I can talk forever. As you can tell, I've been many places. Okay.

So she was angry with me. I think she – I imagine, on her part, she didn't want the world to think that she'd got herself involved in interferon in order to get anything out

of it. So she was eager to protect – she didn't want people to know that she envisaged having a lab of which she would be the director. Although there's nothing wrong with that, but I suppose in her, maybe in her – I'm sure I'm right in this interpretation — she didn't want to be, have ulterior motivation – sort of, to be a perception that she was doing this interferon lab so that she could be the director of a lab, or something like this. So, she didn't want this job, anyway. Didn't want it to be known.

But unfor-, George Galasso is the name of the person at NIH. And I say his name because he became quite a – he was involved in funding issues at the Infectious Diseases actually under Tony Fauci's watch. And I think he had something to do with, later on, in AIDS, he was involved, too, in funding issues from NIH to do with. But, it's a little bit of overlap. And, anyway.

So she was angry with me, we, kind of, that's that. But she would call me from time to time, and say, oh, we just got a grant, and we're having some champagne in the lab, come. You know, it was still a little bit gloating there, and sort of rubbing in my – you know, thing. I'm doing very well, kind of stuff. And just a misunderstanding. I really tried to help, and some public communications didn't work. And so that was that.

And then, the man she hired for the lab was a man called Bill Stewart. Now I knew Bill Stewart reasonably well – I didn't know him personally, but he had a hugely bad reputation, not as a scienti-, he was quite good. He ran his lab. And he did one good thing: he produced the first one-author textbook on interferon. The original text on interferon was a multi-authored thing, of which I was one – it came from 1968 [1967], or so. Still got it, the original. And the first book, comprehensive book on the interferon

system, I was responsible for the making of the actions section. But this was a single author, and it's not a bad book. It's Bill Stewart.

So in 1981, AIDS was first reported. Around about the same time, Bill Stewart had walked out on her. He was running the lab, and he had been involved in setting up – those were the years of biotech companies, people trying to make money. So there was a thing called Key Pharma or something, and Key — you know, K-E-Y. And it was in Florida. And it was a biotech startup. And Bill – excuse me – was involved in this. And so – he walked out on her – just left her. And he left – I knew this, because I was still in touch with interferon. But in those days – well, I haven't told you about the accident, the actions, many accidents had happened. And now, and that happened around about '79, '78, '79. And we're now talking about '81, the epidemic starts. I then started an office; I had to make a living, that's the only way I could do it. At some other point, I can tell you how that happened.

But three months before I started my office, if you said, you're going to be in private, I would have laughed. I wouldn't have – I would have – I'm not a doctor, you know, I haven't done any doctoring for ages. Anyway, I was a quick learner. Or rather, my memories came back, at least sufficiently so.

Which is also the reason why I didn't behave like a doctor. And my patients liked me because I wasn't brought up as a doctor. You know, me, resident, white coat, you patient, and – I had none of that, nothing like that.

Anyway. So I heard that Mathilde – that Bill Stewart had walked out on her. And I hadn't really spoken to Mathilde for like six years now – we had this bad thing

happen. And sort of like an icy stuck between us – more on her part than mine, I think, I didn't.

And then, as I say, I told you – at this point, Kaposi's sarcoma was the most evident manifestation of – there was no HIV then – of AIDS. And Alvin Friedman-Kien is a dermatologist at NYU. He was kind of hogging all the cases, and he made the publicity, and he was getting. And a man called Bijan Safai, who's still in New York Medical College, but in those days he's at Valhalla, New York, I think – but then he was at Memorial Sloan Kettering, a dermatologist. And he wanted patients, and they weren't coming. Alvin was getting them all. It was kind of a nasty competition for people. And there was a lot of show business in those early years. And Alvin was in the newspapers, and you know, he was getting. And anyway, Bijan needed, he wanted to be involved in this, and he didn't.

00:55:00

So he called out to doctors, different doctors, and asked them to come and see him. He wanted to solicit referrals.

So as far as Bijan goes – some people saw me, didn't know my background, thought I was just a doctor. But other people knew me from another life, mostly infectious diseases and so I had a different relationship with them. But Bijan – I'd never encountered him; he was just a dermatologist, and I was another doctor to him, possibly for referrals. So he asked me to come and see him, as he asked others.

So I went there, to see him. And this is how fate works, the most amazing thing. I had just heard about Mathilde – you know, about Bill Stewart doing it, all of us thought horrible, you know, how could he do this to her. And also, even the, more than this, I knew that this company, Syntex company, and the lab had received substantial funds

from Syntex . And that they were due, they, the lab was due to give its report to Syntex – part of what you have to do to ensure your continued funds. And Bill was supposed to go and do it. And it was just at that time that he left, and that left it to Mathilde herself to go and do it, which she did. But it was an added insult, sort of bad thing, that he did.

And so I saw Bijan. And on the way out — going to First Avenue — there's Mathilde, in the corridor, talking – you know, to a group of people. And I felt, despite everything, I just felt so sorry about what Bill had done. And I just stopped her, to tell her that. And she was very pleased, actually, and then told me more about it, and – well, I suppose it goes to the background, of starting the lab, and having Bill and my being sus- . And Bill had a bad reputation. He ended up being arrested. His reputation was bad, not as a scientist; but he was a sort of, he left women with pregnancies, and leaving his wife, and other – and there were all sorts – and he kidnapped one of his children, to take across state lines, and he was arrested. This happened later on.

And – when was the Montreal AIDS conference? It happened then, because AmFAR had a party then, and I was there, and Mathilde was there, and she took me aside, said, I've got to tell you about Bill. And he was arrested. And she said, he asked me for help. And she didn't. She said, what does he think, you know? And she didn't do anything to help him out. And I suppose he went to prison for something.

But anyway, so I saw Mathilde, and I commiserated to her. And this was the first time we'd spoken after — really spoken, you know — after this bad thing, that she felt I had betrayed her. And but now, I'm genuinely. And then we went and had lunch.

And, what are you doing? I told her. And she – that coincided with some other thing that was happening in her life, which meant she had to leave the – I don't know

what the story was there, but I think they were, the institution, Memorial; Mathilde was a fundraising person, and I think she was, I think they rather wanted her to fundraise for them – but instead she was doing it for Democratic Party problems, and issues Arthur was what he was, you know. And she was raising money for other things. And I think — I don't know for sure — but she had to leave.

And so she was looking for something, as well. That was going on. I'm not saying that was a — So we got together on account of this. And at that time — it would have been 1981, '82, something like this — had Michael Callen, Richard Berkowitz, in my office. You know, we were really kind of striking to do things. I had no money, I felt obligated to do whatever education stuff, you know. And – and research. I started, of course, I – immediately got in touch with my colleagues and the people I knew. I had no trouble in putting together a team. Which was the nucleus of AmFAR, actually. And I had no trouble in doing this.

And so I was busy, you know, and – and so she started being very helpful. And that's how – I'm not saying she wouldn't have gotten to it any other way, but that was exactly – I know the publicity story that she told later on through AmFAR was kind of – nonsense. And I went to her, asking for her help. The truth is, that's how it happened, just pure by chance; all related to the bad thing that happened, interferon thing, not talking, but feeling, really feeling sorry, you know.

**SS: So you guys came together, and were doing – so the first time you were doing AIDS research was under, connected to AmFAR?**

01:00:00

JS: There was no AmFAR.

**SS: Okay.**

JS: There wasn't any AmFAR.

**SS: No, but I I mean, was this grouping that produced AmFAR.**

JS: Well – no, that's – it turned out – look; my life was in research. That means – and I had a long list of publications, and nothing to do with HIV or to do with viruses, and – I mean, I did have a very substantial life before this. And that means people; I was connected to people. And here we have a disease that's involving immune systems, it's just right down my alley. I know about these things. I knew about pneumocystis; I knew Kapo-. I mean – I didn't have to suddenly be sur-, I just happened to be a resource that knew. Not that I was particularly on – anyway. So obviously, I turned to people who I knew; groups of people who seemed to be relevant to what was going on.

For example, this apparently was a disease of T-cell subsets. Well I knew that the ability to recognize T-cell subsets in the way that we were doing it was almost as old as the epidemic. In other words, I knew who perfected the technique; it was part of what I knew. And that had only happened in about 1977, '78.

So nobody knew what normal T-cells were. I knew that.

Nobody knew what happens to T-cells, CD4s, if you like, with age, with gender, in health, and in disease. Nobody'd got round to studying that yet.

So there was something from the beginning – totally ridiculously wrong with this whole thing. And – there you are just to tell you this story – I can't, there's too many stories. I'll just tell you this one, and there were others like this.

The ability to recognize T-cell subsets — the technique then was — had been developed, used what we call monoclonal antibodies that allowed a very rapid determination that there were helper cells and there were different kinds of T-cells;

helpers and suppressor cells, and killer cells – that’s what was first recognized. Now in order to recognize these T-cells before this, it was a very cumbersome – it took days and weeks. It was a very cumbersome process. The technology of measuring T-cells was cumbersome until, I suppose it was ’77; it could be round about that time, that these monoclonal antibodies were developed and used to identify T-cells. And that you could do in minutes. Machines were set up, and you could do it very quickly.

Now the technology had been developed by two groups of people. One was a commercial group – they both had commercial backing — but one was totally commercial; Becton Dickinson Company. The other was a collaboration between an immunologist at Harvard — the head of the tumor-immunology at the Dana Farber Cancer Center, and with the author who came with the biotech company as well. I, after about a year — well, months; I don’t know; whenever this disease had — what I didn’t know is that all the publications were what you might call low-level publications.

There is such a thing as the professional medical literature and the professional microbiologic-, immunologic-, they’re different. Now *The Lancet*, the *British Medical Journal*, and the *Journal of the American Medical Association* — even *Science* and *Nature* — are generalized things. But if you really are a pro, you go to the *Journal of Neurology*, the *Journal of Immunology*. There are just other journals that are the more professional journals. And nothing about this disease appeared in any of those things, which I used to subscribe to some of them even.

And I didn’t start to see things on AIDS until late in the – maybe ’86, ’87. So the stuff that was coming out on AIDS, in the *New England Journal* — these generalized things — all came from people – I’d never heard of them. They were infectious diseases

doctors; they were – well, I knew some of the infectious diseases community. I wouldn't – They were – they were not the professional people who – and I have to say another – I'll just – a little digression.

01:05:00 There is a split between doctors and scientists. Which I knew well, from the way I grew up so. When I was working, all the years I worked in the lab; most of my colleagues were Ph.D.s, they weren't medical doctors. I happened to have a medical degree. But the doctors were the talkers, the doctors are the ones, the know-it-alls, you know. But they needed basic information from us, and they didn't really always understand what we told them. You had to sort of baby-talk them, and go through little charts of T4s, receptors, whatever. So then they could talk and pontificate as if they sort of knew the whole. It was a joke – not a joke, but it was kind of, we understood; the doctors had the money, we had to keep them happy. The scientists – and they were paid a fortune. The scientists were paid bullshit, in those years; but we loved our work, we got excited by it, it was – we had our little world. And we had to sort of baby-talk – I'm being extreme now, but just to get – we had to baby-talk the doctors, because they had the authority, they were – god knows what pride – Me doctor, I know everything; trust me, I'm a doctor. All those kind of ridiculous sort of airs and bullshit. And I couldn't stand that myself, you know. That's one of the things that sadly I do respond to, is sort of the arrogance of pseudo, you know, sort of power people who feel they sort of way, and mock the profession basically I think. So I don't like doctors – I mean, that aspect of doctors. I sort of bristle a bit, antagonize them, too.

But I was aware then that the stuff was coming from people who were not the real pros. So maybe about 10, nine, 10, 11 months into the epidemic; I said, well, I'd better

contact the people who do this. And one of the guys who – as I said, who developed the technique was a person at Harvard. His name is Stuart Schlossman. Now he may still be alive – Stuart. These are people – nobody talks to these people.

Stuart Schlossman was the head of tumor immunology at Harvard. And he had spent a sabbatical at my lab. I didn't know him; but I knew people who knew him. So I called a friend of mine in Bethesda, who I knew was a buddy of his. And I said, call him and say I'm going to call. I want to get involved. I want to collaborate on. The right thing to do, obviously. You know, it's a disease of T-cells, who the hell knew what was going on, you want to be involved with people who know.

So Bob Friedman, my friend in Bethesda, called Stuart Schlossman, apparently so. And then I called. And then I called Stuart. I said — I've told this story — I said, I suppose you are inundated, the whole world must be calling to you for help. He said, no, you're the first person to call, and thank god you have, I'm dying to get my hands on material.

So that's real, what I'm saying. And then he told me — I got to know him — he told me that in this institution — Dana Farber Cancer Center, in Boston — there were dermatologists who were seeing people with Kaposi's sarcoma, and they weren't sending him material. They all saw Nobel Prizes, I suppose. They bought machines, you know — they all wanted — never have I seen — oh, that's not true — but this is almost true, though — the science of HIV and the medicine being acted out in the public eye. That tells you there's something wrong. This is show business. I mean, you don't do good work with a camera poring down. Immediately — I don't think, that's unlikely. It's all

show business, it's not the milieu, it's not the environment in which anything – it's just unlikely. I can't say it's not, but it's not very – actually distasteful to me.

So that seemed to be – and so Stuart, a serious scientist, you know – and so he was delighted. So here is one collaboration I had. That's how I started. And I thought things were important, CMV was, and I still do; I'm sure it's important. And so there is a CMV scientist in Staten Island, K. S. Kim, whom I knew, and got in touch with him. And he was very happy to – no money; we didn't have any money, we just did it ourselves. So he was part of it. I thought Epstein-Barr virus, another herpes virus, was important. So I got in touch, I didn't know somebody in Omaha, a guy called Dave Purtilo. And I went out to see him, we started a collaboration. And so – interferon I thought was important. So Mathilde did some work for us in her lab, still. But my friend in Bethesda, Bob Friedman, did others. Jan Vilček at NYU did others.

So we did, you know – that's how I put together a group of people, I just got on with it, just did it, you know.

**SS: And this was under what rubric? What was the name of this ?**

01:10:00 JS: There was no name. It was Joe Sonnabend's office. And supplying material and ideas and thoughts with –

**SS: Okay.**

JS: – a disparate group of people. So when the foundation started — it was called AIDS Medical Foundation — there really – I was getting into incredible trouble, financially. What I did, in those years, I saw patients in the morning – no, in the afternoon — and I went on my own, on my own, I mean, unpaid to NYU, every morning; worked in the virus lab, until about one o'clock; and made some important discoveries –

a very important one of them, actually, that is not taken up. Still, only today, is it being sort of followed, but something that could have been had attention been paid. But –

**SS: What years are this?**

JS: 1981, '82, '83.

**SS: What were some of the things that went on in that lab? Like what were some of the discoveries?**

JS: Okay. Am I doing this right? I tend to sort of –

**SS: Yes, you're perfect.**

JS: – go all over the place –

**SS: You're perfect. Go for it.**

JS: – you know, and –

**SS: Go for it.**

JS: Okay. When this thing – how I came to NYU. Each one has its own sort of – how did I come to go to NYU?

The man who directs the lab at NYU is a man called Jan Vilcek. He's a virologist, he's still in New York. He's become incredibly rich. And in the sense that he discovered a drug. And he became so wealthy that he was able to give NYU 100 million dollars.

**SS: Oh.**

JS: So he's obviously kept some for himself, I presume. And he started something called the Vilcek Foundation. And now, I know Jan – he's a Czech, he's a Czech scientist. In the early years, when I knew everybody, he worked in Bratislava, which then was part of Czechoslovakia. No longer, I mean, they split up. And I even

visited him in Bratislava, in the 1960s, it was still Communist. And he knew – it was a small world, I say, in those years.

And then he made a very dramatic escape from Czechoslovakia, with some help from other interferon scientists. It was pretty, with his wife. He and his, he escaped from Communist Czechoslovakia, in – I suppose it would have been about '67, '65. He had to spend a year in a camp in Vienna, while the Americans were vetting him and sort of checking him out. And eventually, he came to New York, with his wife; right about the same time I first came to New York, a little bit before me. And got a job at NYU, in the virology department. And then that's how I knew him. And when I first came, one of my jobs was at Mt. Sinai, in 19– yeah, I remember, because I arrived just in time for all the Vietnam stuff. I had just arrived at Mt. Sinai, to be met with students who wanted to close the school because of the war. And I'd never experienced any – it's crazy. And then there were the Kent State killings, all that kind of stuff. And really bizarre – I mean, to me – my first taste of American academic –

**SS: Right.**

JS: – this – a real shock. Any rate –

Jan already was there. And I received a contract from NIH to purify interferon. And I had to work with the biochemistry division at Mt. Sinai to do that. And I used to take the biochemists hired for the job to see Jan, to see how interferon. So I knew him reasonably well before AIDS, you know, just for those years. And then, when AIDS started, the first – I heard about it – I can't help these questions {SIREN} because each time, there is something I have to explain.

**SS: Go for it.**

JS: Okay. So my first patient – how did I know about AIDS?

I had a guy with anemia. And I didn't have hospital privilege. I wasn't part of the medical community, I had trouble, you know. But I was a very popular doctor, because in those days – I mean, I had to make a living. That's another story about the accident. We'll leave that and I'll tell you about the – . Otherwise I get totally distracted.

So I found myself running and borrowing twenty-five thousand dollars to start an office at the age of about 46; only because I needed to make a living. I had no interest in any of it. Only thing I knew was sexual medicine. I knew a lot about that, from the infectious-disease point of view. I mean, I knew how to treat syphilis, gonorrhea, all those things. I didn't need anybody's help. But when it came to blood pressure, diabetes, it was another matter. But actually, I managed to do that as well, but I wasn't that competent, in the beginning.

01:15:00

And so – I also had – I was working for the city health department. That's another thing I knew all about VD. I say working, I was at Downstate, I was on the faculty of medicine there. But I moonlighted for the city health department, all of us did, I mean, I was a, despite being associate professor, I think my salary was about twenty-six thousand a year. It was ridiculous, you know. And like everybody else working in the lab, you know, they didn't pay us anything. So we all did little extra moonlighting jobs, you might say.

I moonlighted in the city health department VD branch. So I knew all the clinics, from Brooklyn to Manhattan; all the VD clinics. There were more, in those years, than there are now. And then I worked for the head office, because they thought I knew a lot of stuff. And so they made me their director of continuing education, just a ridiculous

title. That means I did, certainly, I knew what was going on, both with CDC and about sexually transmitted disease. So I knew something about gay medicine and about gay health.

And our director of VD, Yehudi Feldman, who was the director of the office of – we called it VD in those years; VD control; the Bureau of VD Control; Worth Street — and he, at the time when I needed a job, he encouraged me. He said, you know, do a practice. You know how to do it, and you'll get – and I also had volunteered one night at the Gay Men's Health Project. I'd been doing that for a long time. Which was a referral source, you know, but I did it. I was the Wednesday-night doctor at that time. And so I was assured of referrals, so I could make a living. So I started this office, in 1978. So I had two years' worth of – and before long, I was full up. And then I started seeing things, obviously. And full up with gay men, mostly. And I knew how to deal with them, knew how to treat them, and all of that. And so I knew –

So – things were going on. I mean, I saw blood abnormalities. All sorts of things that I understood were not normal. And I tried to – I mean, I did pursue all of these the best I could.

But how did I become aware of AIDS? I had a patient once who had anemia. I investigated as best I could, but there were limits; he needed to be in the hospital, and have further tests. Joyce Wallace – do you know Joyce?

**SS: Sure.**

JS: So Joyce – where is she now, do you know?

**SS: I don't know.**

JS: Was a friend in those days, she is kind of a strange lady, but we were buddies, I suppose. She was okay, basically all right, I think.

I had an office then, on 12th Street. And she was also on 12th Street, a couple of blocks west of me. I was just between Fifth and Sixth avenues; and she was just beyond Seventh Avenue. So I sent him to Joyce for the further tests, and she had to admit him. And they did an endoscopy looked into the stomach. And some purple things were seen in his stomach. Biopsies were take. And then Joyce called, and said, he's got Kaposi's sarcoma. And what the hell is Kaposi's sarcoma? And she then went, I called the cancer institute, and asked to refer for a specialist in Kaposi's sarcoma. And she said, they told me that Alvin Friedman-Kien at NYU has 12 – I don't know, some number – and they're all in gay men. And that's how I first knew.

And I said, well, I know Alvin, I do know him. And so I immediately called Jan Vilcek – he was the head of the lab.

Alvin was a dermatologist, but he'd kept, he always got a little bit of a grant for some laboratory work, and he kept a technician in the lab. So I'd met him there, you know, and times going to see Jan yeah, who I knew well, and his wife was a curator at the Metropolitan, in drawings. And – yeah, they used to have – yeah, they were part of my social life, as well. And –

So I called Jan. He said, yeah, it's absolutely true, speak to Alvin. So I spoke to Alvin. Yeah, it's absolutely true, it can't be – So I mean, I just – I'm coming. And – that's how I installed myself at NYU.

Oh, I was very much welcomed; there's no question – Jan knew me for years, as an interferon scientist.

**SS: Now what year was this discussion?**

JS: '81, I suppose.

**SS: '81.**

01:20:00

JS: The same year that it happened, yeah –

**SS: Oh, wow.**

JS: – in the beginning, very beginning. All this is going on, you know; but not being of any interest to what passed for the leadership of the gay community – don't even think about them. I mean, you might have been on the moon, as far as they were concerned. Not to say that accept AIDS. They did their best to do me in, but that's another matter. They actually succeeded, to their loss, I must say.

So anyway, I went to Jan's lab. So that's what I did. Every morning, I was there; weekends; one o'clock, I had to go to my office, see patients. And – so you asked about discovery there. So – we didn't know what to do with the patients. I had an interest in CMV, so I really involved K. S. Kim. I got some CMV virus, I started to do that myself, in the lab, growing CMV. Then one day – we spoke a lot, you know – ideas, what could it be, and through Jan, that meant whatever other the official such as it was, I was a little bit aware of a beast NIH tried to do, tried to convene, I did convene some early meetings, which I went to, just to get ideas about what was, which ways to go, and – it was a very unseemly time, too, there was a sort of competition.

Also, the better people didn't want to get involved in it, for a variety of reasons. And that's an important thing that I was aware of, because I was living in that world, and I knew, I knew that – I knew that – it was mistaken to think of scientists as being dispassionate, in the sense that I was well aware that many of my fellow scientists, with

whom I sort of lived in that, were – sex-phobic, homophobic. Not in any structured way. They were just human beings who were squeamish about sex, maybe that's all. But particularly squeamish about homosexual sex. Some were antipathetic, you know, hostile. But they were human beings.

**SS: Uh huh.**

JS: And there's a huge, big mistake of thinking that scientists are, you know, kind of – but I knew very well that – I didn't – they were just people. And as such, I think not to be trusted with – heh – being particularly concerned about the plight of gay men or drug addicts or black people. I don't know why they were just as bigoted as anybody else.

Any rate. So here I am. And one day – Alvin and Jan and me are sitting in Alvin's, in Jan's office, in the lab. And – something happens. They both go. And I'm left in the office, and there's some preprints on the table. And either because one of them was going to back – I was sitting there, and I think Jan was going to come back, or I can't remember the details; but I saw this paper. And the paper was a scientific paper which said that an antibody to T-cells was able to stimulate the production of a particular kind of interferon, interferon gamma, in the test tube.

Now, I thought, oh; this is interesting. Because, at that particular point, since we didn't know what to do, we did everything, heh. Every test we could think of, we did, on our patients. What else are you going to do, in those days?

So amongst the tests that we did, or asked for, was a test for tissue typing. Everybody has a tissue type, in the way that, you know, we have blood-group types –

**SS: Um hm.**

JS: – and we all have a particular tissue type. Human beings; we call these the HLA anti-, for the reason that, for example, transplants don't work – you reject transplants – the only transplants you will accept will be from somebody of the same tissue type. So it needs to be an identical twin, or somebody by good luck, happen to be close to your tissue type. So each person has an individual tissue type. And this is made up of a complex of antigens. So your tissue type would be described by a variety of, a particular combination of different proteins that appear on the cell, which your body recognizes as you, so it doesn't destroy, unless you've got an autoimmune disease. But if somebody else's blood is put into you, let's say, or tissues are put into you, from a different tissue type, your immune system will recognize that, and will zap it with antibodies and stuff like that; you know, T-cells.

01:25:00

So I could tissue type; you, me, we all can be. So there are techniques for tissue typing. And so we sent, so one of the things to do; we sent tissue typing. Because it could be that this was a genetic thing about this disease, so that maybe – people with the disease had a preponderance of one particular combination of tissue type antigens. So, because there were infectious diseases already recognized to which some tissue types were more susceptible than others so. And some diseases are totally connected with particular genetic tissue types.

And so this wasn't one of those, obviously. But anyway, so we did this. And this was being done by a man called Pablo Rubinstein, at the New York City Blood Center. And he was married to Cladd Stevens, another scientist who was quite important in the early epidemiological days, actually, Cladd Stevens – first with hepatitis, and then did some stuff with HIV.

At any rate, Pablo Rubinstein reported — he told us — that he couldn't do the tissue types very easily, because it seemed as if the lymphocytes from our patients, which he was using to type didn't — there were technical problems. And the technique that he used was an antibody technique. In other words, let's say your tissue type could be — it's a unique combination of A, B, D, whatever — of components. And we all have these components, but in different combinations and different — so each of us is unique, in the way we display on the surface of all our cells; which tells our immune system itself, don't kill us. And so it can recognize something that's not self, and kill it — whether it's a bacteria or a tissue transplant, or something.

But tissue type depend on an antibody, specific antibody, sticking to a particular antigen on the surface of the cell being typed. And Pablo couldn't get these to stick. He said, it looks as if, he said, the cells themselves are coated with antibodies.

So I just read this paper of Jan which says, an antibody to T-cells can get that cell to make gamma interferon. So I said, if that's the case, maybe these guys have got gamma interferon in their blood.

**SS: Huh.**

JS: And — here's a good example of a bad idea turning out good. And actually, it turns out to be right. One of those wonderful things in science.

So Jan comes back, and so, okay, we'll check it out. It seems — because they do interferon assay, the patients were there, you know. And so we do these assays — in the lab, they're done. And it turns out these people have — bags of interferon in their blood, huge amounts of interferon. And this has never been seen before, other than during a virus infection. And then even when it's seen in a virus infection, it only lasts for five

days, because if there's something wrong, there are mechanisms in the body that turn off interferon after about five days, because it does its job in trying to get you on the road to recovery. And then the body turns off interferon, because there is something damaging about sustained presence of, so we understood that. But in this case, these guys had huge amounts of interferon, day after day, and it just never went down.

But it wasn't gamma interferon, it was another, it was alpha interferon.

So the idea was wrong; but it led us to do something. And we found another kind of something. This is one of, I think, a great story of how science works. You have an idea. And as I said earlier, the importance isn't that the idea needs to be right or wrong, but it gets you moving.

**SS: Right.**

JS: And in the movement, something comes that was unexpected. And as it turns out, years and years later; there is indeed gamma interferon. But the technical means of — we didn't have the technique of sensitively picking it up. So there is actually gamma interferon.

But anyway, so that is a really critical thing, as we know now; that people with AIDS have activated immune systems; and interferon is a manifestation of activated innate immunity, which was discovered in 1981. And nothing was done with it. Why? And this is part of one of my sort of bad lessons, or as I say, bad lessons, lessons that led to bad things — why was this aspect of pathogenesis not pursued? Why did Tony Fauci — not the sharpest knife in the drawer, as they say — modest imagination, nothing very much there — why was funding or any idea of pursuing a potential role for interferon in pathogenesis not pursued? It was a huge abnormality. The only other disease in which,

01:30:00

in the same lab — Jan's lab, and my friend Bob Friedman at Bethesda, had been instrumental in finding this out, too — the only other disease in which large amounts of interferon appear for long periods is lupus — autoimmune diseases. And some of the treatments for autoimmune disease use anti-interferon therapy.

And so why — but why — there are many — this is one of the big puzzles, to me — I thought, why is there no funding, no interest in pursuing this? Any number of examples beyond that. But it's — one — there was a meeting at NYU, maybe in the early 1980s. And at that meeting there was a scientist from the Schering company.

Now, large amounts of interferon were produced by recombinant DNA technology in the late 1970s. And there was no use for it; we couldn't find a disease — maybe hepatitis B, but you know, but they stockpiled, at huge expense. Both the Schering company and Roche — the two companies that had in those days produced recombinant interferon. Wonderful, we've got all this wonderful purified recombinant interferon; but nothing to do with it. Who are we going to give it to? It was in search of a disease.

So at this meeting, there's, his name was Reuben Somebody, and I can't remember the rest of his name. An interferon scientist, you might have encountered. And Tony Fauci gave a talk there. If I remember, one of these funny things. Before — in the intermissions, or in between things, I caught a glimpse of Tony, in the pay phones. This, I don't know how they are today, but they all had, there were some very bright chromium little strips that you could see yourself in as if there's a mirror. And there was Tony, sort of positioning himself this — looking, getting himself looking nice, I suppose. Producing these little strips of paper, and — just kind of funny.

So this guy turns around – you know, we, in the Schering company, we produced – a huge amount of recombinant interferon. And we – it's just sitting there. And AIDS or something, you know, this is even before HIV/AIDS, or something. Let's use AIDS. And use it, let's use it for AIDS. I found that kind of a little outrageous, but, you know, that's the way of the world, and I can't say it sort of so direct, but that's sort of the dynamic that he told me – which seemed about right, you know, that they were –

And so – and in fact so it was. Tony Fauci and many others were pumping into, gaily pumping into – and killing people, actually. A lot of things are never spoken about.

**SS: Because interferon actually cannot successfully be used to treat HIV disease, right?**

JS: Why on earth would you do it, when people have got interferon in them already?

**SS: I see.**

JS: What's the point of giving them more?

SW: These guys were bursting with interferon already.

**SS: I understand, I understand now.**

JS: So Tony Fauci would say –

**SS: Okay.**

JS: – I've got droci-...

**SS: –**

JS: He came to – nobody would listen to me I'm afraid. He came to the Community Center in New York, to answer questions once. And I don't know why – I usually don't go to those things. But I went to this one. And somebody kept a tra-, I've

got a transcript of it somewhere. Somebody kept a transcript of it. And so – there's questions and answers. So somebody pops up – his name is there on the thing.

Dr. Fauci, People with AIDS have got interferon in their blood. Why would it help them – well, something like this – give them more interferon?

So he said, well you've got to understand that the interferon that people have is a totally different drug. It's something different. And – it's a different thing.

And then he says, he sees me. S-, I knew, I knew Tony Fauci before all of this, you know. I didn't know him well, I only knew, I, you know. He knew, certainly, who I was. I'd, we'd spoken, you know, I had met him at meetings and things, before AIDS. And just random before AIDS even. And so then, the oh Joe, you look puzzled, or something.

And I said, well, you know, it's the same molecules; it's neutralized by monoclonal antibodies to conventional interferon.

Oh yeah, oh. And then, next question. And that's how it goes.

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So there is something – he must have believed that, or something.

Then, on another occasion, I went with Mathilde, actually, to the Institute of Medicine. There was some kind of meeting about AIDS. And he was on the panel, and people gather. He was kind of the moderator, and there were people giving presentations. And one of them was a molecule called beta 2 microglobulin. For some years – this, you can pick this up in their blood — for some years, beta 2 microglobulin was touted, was promoted, as — because you can test for it easily — as an adverse prognostic mark. In other words, if people had a lot of beta 2 microglobulin, then their outlook then was bad. You could sort of make an adverse prognostic assessment.

But I knew — some of us knew — that beta 2 microglobulin is a kind of surrogate marker for interferon. Because — there's a huge literature that says that if you give people interferon, then they make beta 2 micro-, that is the natural stimulus for the production and release of beta 2 microglobulin interferon.

And so somebody had given a talk about beta 2 microglobulin as a prognostic — and I was — seeing this arguing she knows about these things. And I was uh, uh, uh, uh. And, being a little indignant, why don't you speak about interferon. So I don't like, generally, sort of doing public things, but I couldn't contain myself, so. I went to question time, I had to go to get up to the microphone. And I said it's kind of remarkable, these people have got tons of interferon in them; and why is it not mentioned, I mean, circulating interferon is, is, he interrupted.

Tony said, does anybody know and I know the next word we're and we know what he's talking about? And it was so obvious, he sincerely was saying — and somebody interrupted him, and said, oh no, interferon assays are much too expensive for us, so we're doing this. So he came to somebody else, I don't know who it was, came to my rescue.

But that sort of indicates, I mean, I don't think Tony Fauci knew the connection between beta 2 and interferon. And that doesn't surprise me. I mean, other instances where he just hasn't known. He just hasn't known. He's just a gumphing sort of, you know —

**SS: So would you say that in those early years, people died because of this —**

JS: Yeah, of course.

**SS: — idiocy on the part of AIDS —**

JS: Well – I mean, what's sort of is that they would have died anyway –

**SS: Right, right.**

JS: So all one can say is – their death might have been hastened. But there were other, many examples of things that could have been done that weren't being done. And so here's an example of a discovery, made at NYU, that is published. The story that I'm telling you has been published. Jan Vilcek felt the need to write up this story that I've told you, because it's kind of a neat little story about Joe sitting in my office, reading this. It's there, it's in print. And – not that anybody would necessarily notice it, but it's still there. And so for those of us who know.

But there are other things, like PCP prophylaxis; and many things that could have been done, and that attention was drawn to it, to these things, but – not this generation, maybe, because we're too close to it; but a future generation, I think, might ask these questions.

**SS: Well, for example, excuse me, Bactrim was the first, I believe, successful treatment of an AIDS –**

JS: Not treatment –

**SS: Prophylaxis.**

JS: Prophylaxis.

**SS: And so where was that, where did that insight come from?**

JS: Ah. There's no – another history to many of these things that you don't know – I mean, I'm not surprised.

**SS: I don't.**

JS: Why would you?

## Part II

JS: – uh, particularly, you know, instead, when you've got the heroic story of Larry Kramer saving the world, or something like that.

**SS: Oh, that's not my story. But go ahead.**

JS: Well, not yours. But I mean –

**SS: Okay.**

JS: – those are the stories out there. It's, you know, forgive me, ACT UP saved the world. But there are a series of other stories – which are out there, but nobody – so Bactrim is a good one.

Bactrim is a very cheap drug; generic. And in the 1970s — my dates are a little bit wrong — in 1977, the use of Bactrim to prevent PCP was worked out, in a double-blind, placebo-controlled trial, amongst leukemic children, in Memphis, I think. Somewhere in the South.

Oh, the noise. Maybe could we close the window, Simon? I've opened the window because it was hot the other night. Thank you. If you want some more coffee or have a bite of something.

**SS: Okay. You know what? Instead of going through the Bactrim story, let's stick with you.**

JS: All right. I'm part of the Bactrim story.

**SS: Oh, okay, then go ahead.**

JS: I am the Bactrim story.

**SS: Please go ahead. Okay, let's hear it.**

SW: Also, the AMF origins, too, you need to get back to at some point, Joe.

**SS: Okay.**

JS: I should also that all this stuff I'm telling you, almost all of it, has been written. It's there. And interest had been shown – it would have been easy to find all of this. And I should just say. I'll tell you about the Bactrim – It illustrates something. It illustrates that egregious negligence, if you like, has been brought to attention repeatedly; and yet, those people who claim to be protecting a community — in this case, of people with AIDS, or even more specifically, gay people with AIDS, and it could be drug-using people, or whatever have chosen — has been brought to their attention, but yet, they have given the perpetrators of this negligence amiss? They allowed them to continually make mistakes, as it were, even when it's brought to their attention, they seem to just shrug off. So in other words, I find this completely – It's as if they're persecuted, and I'll use one, a group is in such awe to their persecutors and the scientists amongst them that they permit them anything.

Beat us up; fine. Beat us up again. Deny us PCP prophylaxis. Give us too much interferon. Eh. Don't follow that research avenue, but the steering of – And give you more money, more money. There's something –

**SS: Can you tell us some of the names of these perpetrators?**

JS: Who? Doctor – the names of the perpetrators?

**SS: Yes sir.**

JS: Well, the perpetrators – let's put it this way: there's not, individuals. There is a – well. Who – then I'll put it another way. If it's known, if it's known – that a drug can

prevent a dreadful opportunistic disease that produces a grisly and horrible death; by suffocation; and that drug costs nothing; and it is not promoted, and not made available; who is the perpetrator? I mean, it's not as if there's an individual, it is a conspiracy – not your conspiracy in a sort of conspiracy sense. But if there's a, it is a conspiracy, nonetheless, as sort of an agreement to not rock the boat, because, for complex reasons. Maybe because there is an establishment, such as it is, holds a huge amount of power. And even if it's nebulous, and the power is power of funding. I mean, there is, in other words, in addition to that, or maybe part of the same thing; is the deference shown to authority. And so authority is conferred merely because you happen to be a Harvard professor. You can be full of shit, basically, but it doesn't matter; you're a Harvard – in other words, maybe we have such a need to have authority structures in place, for our own stability, maybe, that we don't care if that authority is putrid –

**SS: Uh huh.**

JS: – and doesn't – I don't know. So I'm not saying who the perpetrator – we are the perpetrators, by allowing it. We permit people in authority to dominate our lives. And maybe we need that; we need that for stability. I don't know, but instead of us questioning – so we allow them to make mistakes.

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So who denied people PCP prophylaxis? Whose responsibility was it to have provided then? That's who, I'd say, who the perpetrators are: the people who – if there are people who have responsibility to provide the best treatments to prevent suffering and alleviate suffering, then they are the perpe — The ones who should have done it didn't, and I can't say who they were. But the instruments of this structure would be the Doctor

Faucis, the NIH; the people who have taken on the medical leadership, all these sort of fancy they call them the celebrity doctors, the AIDS doctors are all celebrity doctors.

**SS: Like who?**

JS: Like rich men. I don't, there are a whole bunch of them, and people whose names are on – they are the ones who – I get a journal; and I could just trot off the names of all that. I don't think as individuals they are evil people.

**SS: Okay.**

JS: It becomes too trite and facile. But they are instruments of the medical power structure, if you like. Which, at the end of the day, probably is manipulated by the drug companies. But to say that is kind of like, you know, conspiracy. But it doesn't work directly, but we are beholden to those who fund us, at the end of the day.

**SS: Well, would you say that because Bactrim was not a highly profit-producing drug; therefore it was not promoted?**

JS: No, I don't think so.

**SS: No. Okay.**

JS: I don't think so. I would – if I have to hazard anything, I'd put it this way.

**SS: Uh huh.**

JS: The health of minorities, whether they're ethnic minorities, sexual minority, any kind of minorities — we know, traditionally; we just know; all of history tell us that the health of minorities are not a concern of whatever establishment exists. It just isn't, and we just know that. We know that particularly for black people, whose life expectancies are what they are; we know that from the health of sexual minorities. Nothing to do with AIDS; we just know that.

So the question you're asking me is a question that could be put to that: Why, why is that the case? That's really the same to why is that? It's not a simple answer to it. But there is an answer to it, and that's why Bactrim is not.

The motivation – there is no – we accept that the health of minorities is abysmal in developed societies. And I think things may be changing now. But in 1980, that's the way it was. Black people have Tuskegee to remind them. If only gay people would understand that Bactrim was their Tuskegee, or other things like that instead they want to share power with the people who deprived them of the best solutions, for some reason I don't really know. Maybe they don't want to think of themselves as a minority. I have no idea. It's not – I just note it.

**SS: Okay.**

JS: So I don't know. I would say that Bactrim was denied because a community who could have profited from it didn't ask for it – I don't know whether that could have got it for them. The people whose responsibility it was to look after them had no compassion or interest –

**SS: But Bactrim did become the standard of care.**

JS: Yeah, but only after how many tens of thousands of deaths later? You can't stop it forever. Yeah, it did, in 1989.

**SS: 1989.**

JS: Yeah. It was recommended. It was a little bit ridiculous. And if we put it another way: leukemic children get AIDS. People with HIV with AIDS get AIDS. I mean, AIDS – get PCP now. So do people with kidney problems. And all sorts of people did.

Now in 1981, if you weren't a gay man, or a drug user, or you didn't have AIDS; and you were at risk for PCP; there was a good chance you'd get Bactrim.

Now why should society work in such a way that people would be willing to give Bactrim to a kidney transplant. They didn't do it everywhere. Some centers did.

But people with AIDS, it wasn't recommended. Despite the fact it was being – me. I suppose nobody was asking for Bactrim in 1981-82. But I knew – I mean, I'm an academic physician, that's most of my life before, so it's my business to know. I had to teach medical students these things. And anyway, I guess, kind of knew these things. And I knew about Walter Hughes, the man who did the work on – here's an interesting thing.

00:10:00 Walter Hughes is the infectious-diseases doctor who worked out Bactrim for leukemic kids, in 1977. In one of his articles, which I had then, have now, he said, well, we've done it for leukemic kids. But you get PCP in other conditions. And he said — his recommendation — he said, well, in those other conditions, which we haven't studied Bactrim, we have to assume that it will work as well. And what we suggest is that whatever the condition is, if the experience is that there is a recurrence of PCP of greater than 15% in one year, 15% I think he said, then those people should be immediately given Bactrim to prevent – that they would be considered to be at risk.

Now by 1986, at least, and maybe before, we knew that for people with AIDS the recurrence rate of PCP after one episode was something like 70%, most people would get it. So that's well above the 15 percent. And, okay.

Now the reason I bring this particular one up is that Walter Hughes was on the advisory committee for NIH. How do you tally all these things, you know? It's – if

there's been kidney problems, it would have been the same thing. So I suspect, in some kinds of ways, the fact that AIDS hits marginalized populations has trickled, in its complicated way, and not ways that one can sort of easily kind of define the steps involved; but how can one be sort of ignorant or dismissive of the possibility that the attitudes – I mean, marginalization itself carries burdens; and how can one be sure, really, that people involved in science, medicine, etc. are themselves not operating in the same universe, which I think they are. But one can't pinpoint; I don't think they're necessarily bigots or homophobes. Some are, some are not.

But the whole structure of it means that we have these peculiar things where we have a community who know that they've been badly served, in many ways; and yet they give their – a pass – there's no, gee, well, he made a mistake there — on to the next mistake. So this is just something one observes, and it just seems kind of strange.

**SS: All right. Then let's talk about AZT.**

JS: Okay, same thing.

**SS: So you were a very early person, in terms of understanding that AZT was a mistake.**

JS: Yes.

**SS: So when you started to speak out about it, I know that you faced a lot of opposition. But history has proven you to be correct. So do you want to discuss that experience –**

JS: Well, sure. But it's really part of the same thing. How is it possible? Now, all I'm saying is that these — and I'll come to AZT — I'm saying is that I don't think everything is motivated by, I say motivated — can be explained by the fact that the

people involved are marginalized, and this is just yet another further expression of what it means to be marginalized. You don't get the best. Huh. I mean, it just – so, yeah.

So that sort of operates in its sort of complicated, poorly defined kind of way. But at the same time, the same sort of things would happen even in populations who are not marginalized. Bad things happen to people who live in Scarsdale, I suppose. So it's not just simply that.

So, what I have noted, though, is that – let's say, a conflict of interests and exploitation across the board. I don't think – they're not focused particularly on marginalized populations. But what I had noticed is that when these things happen — and I'll give a concrete example — when they happen, it occasions discussion, as much discussion about – not that it changes anything, though it might moderate some. But when it comes to HIV, there's never any discussion, there's just simply silence. That I just noticed. But the explanation that I don't know, and I can give you a concrete example, but maybe I'll just quickly do, then I'll come to AZT.

I have noticed, over the years, that clinical medicine in HIV is riddled with conflicts of interest. But so is all of medicine. It's nothing very peculiar about this.

The interest in, in other words, people on advisory committees who are on the take, basically, who get consulting fees, et cetera. It's common; everybody does that. A few principled people. I don't, but – But in every field, there is discussion, what people say is discussed, and why people point it out. But it doesn't stop it. It may be moderated a bit.

00:15:00

In the case of HIV, it's zero. The rest of the world is not looking at HIV. It's happening in a cocoon, I've noticed this.

Now to give you a concrete example of this – something that illustrates it to me, just quite perfectly.

There are a number of discussion groups on the Internet that I, that deal with – what prompts them, or the motivation, is a concern with the undue influence that marketing has on clinical practice. And so people are obviously concerned, across the board. With cardiovascular medicine, psychiatry, whatever; the undue influence of marketing on the way that doctors are got to, and induced to prescribe for this and that disease, are invented. All sorts of bad things happening.

And so that is not going unnoticed by people. And I belong, I have belonged to these groups, and have taken part in these things as well.

And round about 2000, end of 19--, I was aware that in HIV medicine – these groups never spoke about anything to do with it. Zero, never. And this just never came up. So I tried to interest them, and I would insert something. These are groups not involved in HIV, but involved in everything else.

And I tried very hard, and I just gave up. I really gave up. Because I used – I come to AZT – I used, this one site called Healthy Skepticism, which may be one of the better ones. It's nothing to do with HIV. It's run out of Australia, at the University of Adelaide. And it's a membership, I even paid my dues, you know. But you can also access it – just back and forth, the whole time.

And I wrote to the guy who runs it, and I brought up the HIV. I said, what about the AZT trial that led to its approval? It's never been commented on, never been criticized, other than by me. But it has never been criticized in any of the journals. It's a horrible example of bad interpretation of data. And he said, okay.

So I wrote something for him. And he said, I'd better check it with an infectious diseases doctor. And he then wrote back, and gave me the comments of the infectious diseases doctor. And eventually, who actually said: oh, they're doing wonderful things in HIV medicine and so I don't think we need to go there to criticize. He wasn't interested. You know, they're doing great things in HIV medicine, this and that.

So it enjoys – so here's the example I'm going to give you; the same Healthy Skepticism.

Maybe about three or four years ago, I saw an article in a posting there from somebody here in London; a TV doctor, a person who commented on the recommendations made by the International AIDS Society on when you start treatment, and what you start with, as it was in, say, 2011 or '12, something, I can't remember when it was. And then he pointed out that all the members, he saw their conflicts of interest. That all these members, they're all connected with this company, that company, this company. And they're making recommendations which affect the financial status of the company that paid them.

So that is such an obvious conflict of interest. And even if they resign, have the revolving door stuff. So he pointed – and it was printed.

So I had written — there was a blog I used to do sometimes — on the same thing, about the NIH recommendations, where I gave things to the financial – it was so in-your-face, you know, whether it's – where they recommend a treatment even in the absence of good clinical data, based on expert opinion. The experts are receiving like a huge amount of money from Gilead –

**SS: Right.**

JS: – fees. And who's an expert? Their marketing people can make you an expert, calling you an expert, or a decision-maker, or a thought leader. I don't know what they call it. Key opinion leader. I don't know what – they invent these things, and they confer on you, it's just some snit in the marketing department makes you an expert, all of a sudden. And then you say something, and experts agree that this is whatever. And this is – as I say, this happens in everything.

00:20:00 So this man was called Tom Yates, who wrote this thing for Healthy Skepticism. And I was sort of emboldened by this. So I reproduced for them the thing that I wrote about the NIH's conflict of interest, and they printed that. So he got in touch with me. And we decided, we spoke. And he has nothing to do with HIV. And we spoke about what I'm speaking to you about the fact that in HIV, medicine is just a cocoon. Things happen, you can kill people, and nobody pays any attention.

Well, these things happen in other fields, too. But as I say, there's always a bit of a hubbub. There's a kind of comment and discussion. It changes things maybe, a little bit. But HIV medicine is notable by silence.

So we wrote a letter to the *Journal of the American Medical Association*, which they published; me and Tom Yates. We point out this conflict-of-interest thing. There was almost no – The chairman of the thing was Paul Volberding, and Melanie, what's her name, in Atlanta, Melanie Thompson, who are the chairpeople of the committee. And they both wrote to me individually, personally – pathetically, actually. Paul says, oh, we don't need any evidence. We know that early treatment works. Now they've gone and done their thing. We don't, god, I don't know if Paul – And he wrote to me, and Melanie also wrote to me, just personally, to sort of defend themselves.

Anyway, I bring this up to say that here is an example of bringing up a conflict of interest — one of these issues in HIV medicine — which didn't go anywhere, but if it was unusual, it's just not that you can go through Healthy Skepticism, other sites. I have names of them. Almost never — can't say "never" — but you hardly ever see anything related to HIV medicine. So it's as if they enjoy an immunity to scrutiny. They live in their private — and you can say anything you like. And that's why so many of the trials, and I'll come to AZT now are — they do not support, many times really don't support the recommendations that come. All the recommendations, if you look at all the recommendation about drug treatments, they all favor more drug treatments. Everything — so now the whole world's going to get treatment and so. But no comment.

This could happen in cardiovascular medicine and psychiatry. But there would be a buzz. But in HIV nobody wants, in other words, I've noticed this from the beginning: it's kind of, they don't want to look. It's a kind of not respectable.

In the same way, when I started looking at gay guys who have sexually transmitted infections in New York; I knew then, because it was around, that doctors don't want to do VD — American doctors. It's kind of — it's not rational. They just don't feel comfortable about it. Whereas in England, it's called genitourinary medicine, and these attitudes don't apply here. There are perfectly good specialists in genitourinary medicine, who know all about syphilis, et cetera. And you can go to them, and they're expert. But in America, it's a substandard thing. There are these irrational things that operate.

So HIV, because it affects marginalized — I'll put it another way. Ask this question — I would ask this — just ask it.

Would you say that the fact that the individual who have been predominantly affected by HIV/AIDS belong to marginalized populations? Would you say that that fact has had an impact on the response?

**SS: Of course. It determines the response.**

JS: Then how, then how? You know. In what –

**SS: Neglect and indifference.**

JS: Okay. And then give the example. Yes, exactly right. But we don't say that, do we?

**SS: Hm.**

JS: Not, we don't say that. Instead, we prostrate ourselves in front of Dr. Fauci, and give him an award.

**SS: Okay.**

JS: I don't know how you, I don't know. Best buddies with Larry [Kramer]. I don't –

**SS: All right, all right. So let's get back to AZT.**

JS: Okay.

**SS: Okay.**

JS: Well, if you put a question like that. And then, you say, of course, indifferent. But then you say how. You know, give me the examples of that. And I think I'm giving some, by the lack of scrutiny, things like this are –

**SS: Yes. Of course.**

JS: – just manifestations of something that we actually all agree exist. Okay.  
AZT.

First of all, AZT is the nature of drugs, it's a nucleoside, it's an analog drug of one of the building blocks of nucleic acid. I'm an old, old — well, I am old — and — microbiologist. I've worked with these drugs. Now when I worked as a laboratory scientist, we used these drugs as radioactive traces. They would be incorporated into RNA or DNA, and then we could follow — the way of following — you put the precursor, which had a radioactive tag —

**SS: Mmm hmm.**

00:25:00

JS: It would get incorporated into DNA, and therefore you could actually examine the way that DNA is made by following the radioactivity of the component.

So in those days, AZT — like drugs, we felt that they were dangerous. So in the lab, we kept the concentrated solutions, which we used. And only us, the scientists, would go there and dilute it before we'd give it to the technician. We wouldn't let the technicians handle the — And this may be taking it a bit far. But these drugs, showed the respect we had for drugs that mess with your DNA.

In medicine, I knew that we did use drugs like that before AZT; but we only used them for a short period, like in cancer therapy. You don't put people with cancer on lifelong treatment. You treat them for weeks, months, I don't know. And there was no precedent for you. And the idea of using a DNA-altering drug for the rest of one's life was kind of like not — my generation of people would — this brings us to another thing about medical education, huh, and about the people taking on this epidemic, and how, I think, poorly educated they were —

**SS: Okay, I'm going to interrupt you here. I want to ask you a question.**

JS: Go on.

**SS: Before, we were talking about treatments in search of diseases. Isn't that the case with AZT?**

JS: Uh – I don't, I would say so, but I don't think that was the predominant reason for it.

**SS: What was the predominant –**

JS: I do believe that the NIH wanted to make a publicity killing; basically that they were on top of it, they'd come up with a – because that was in the air. We have to find a cure, it wasn't even just activist stuff. It was, here's this mystery disease, and Margaret Heckler had just announced the stuff – and it was the need to come up with a show that American scientists were on top of it all, and had a cure.

And – more interesting question, or a question might be, unfortunately, is if this disease had been across the board, not been so localized in marginalized – would AZT have happened? And I suspect it may not have happened. And so that would be another example of –

**SS: Because you're saying they didn't really care that it didn't work. They just needed something.**

JS: Yeah, I think so.

**SS: Okay.**

JS: Yeah. And I think they – and the things that – so I'll tell you about that – AZT.

Firstly — and I won't go on about it — but firstly is the use of a drug that goes to the heart of DNA is not, is kind of big, serious stuff, in my training.

**SS: Right.**

JS: I mean, you don't fool with things like that. You don't. So the use of AZT was already kind of suspect to me, just because it belonged to a class of drugs that one respected –

All of those things, I think, have changed a little bit, so there's a difference in the way that doctors operate, and I think medical education has changed some. I don't know that a younger generation of doctors would feel quite the same way. So that's nothing to do with AIDS or marginalized – so that's one aspect of it – there's that.

But the reason why I had problems with it is — I'll tell you now — the trial that was done was a multicenter, it was done in many different centers, I think it was 11, 12, or 13 centers. And one of them was New York, at St. Luke's. When the results were presented to the public — a press release, and things — it was very dramatic. And I think my recollection would say something like this: there were a hundred and fifty people, roughly, in each arm; in the placebo arm and the AZT arm. And people on AZT, in the space of 12 weeks or somewhere in there, when they stopped the trial; one person died. In the placebo arm, 19 people died. And this was so dramatic that we've got a life-saver here, you've got to stop the trial. Everyone has got to get AZT.

Now, the people who entered the trial included people who'd had one episode of PCP, or had what they used to call ARC in those days, which was a – you know –

00:30:00 So what immediately made me a little bit suspicious was the fact that of my patients who had had PCP, I certainly didn't expect them to die in 12 weeks. Absolutely not. In other words, I knew that if my patients had been enrolled in the trial, nobody would have died in 12 weeks. So AZT, in the placebo, I mean –

**SS: Yeah.**

JS: And so I thought, what's going on here, you know? There's something wrong. That was it. Why did so many people die? What's going on?

I certainly wasn't going to give people AZT. I didn't need to. I could keep them alive without any of that kind of stuff.

So I then – for some reason, I was – it must have been the last time I had a respectable relationship with Martin Delaney. Because he was happy to get, through the Freedom of Information Act, the submission of Burroughs-Wellcome to the — I say “the last time” because after that he, I think the only thing he would have willingly done for me is sort of put an end to me. And he became quite hostile. He didn't like what I wrote, anyway.

But the thing is that the copy he got for me was blacked – a lot of stuff was – god knows why – I couldn't read it; there were too many black –

**SS: Yeah.**

JS: – blacked out things, you know, for it to make any sense. So ACT UP New York got me another version, which was perfectly legible. I never did compare the two to see what did they feel they had to black out, you know. It would have been interesting, maybe, to do that, but anyway. So I got a clean copy of it all. It took me about three weeks. I'm going to find out what happened, how did they get this result. And so the first, I like looking at data, you know.

So the first thing I did was try to find out why people died. What were the actual causes of death? And – you don't die of AIDS; nobody dies of AIDS.

**SS: Right.**

JS: You die of an opportunistic infection. And you know that – some of them you can prevent; some you end up, if it's going to kill you, then whether you live or die in the short term depends on how quickly you diagnose it, how aggressively you treat it, how you treat it. These are things that are going to cause death or life, you know? And so that's how I kind of looked at it.

And the causes of death were not very well – they were maybe about 70, 80 – I've written, I've got it somewhere – about 70, 80% of them were probably recorded as PCP or toxo[plasmosis]. Others were poorly recorded, like "AIDS." There were some – it doesn't matter. The fact is that most of them were opportunistic infections, documented at least. Also discovered there weren't proper diagnostic things. A lot of sloppiness in AIDS, but you know, that happens. You can't help that, in a complicated multisite trial.

Another thing I discovered was that the deaths were not uniform. They tended to happen in certain places. And one of the site was New York. And nobody died in New York. People died in San Diego, people died in Florida. But some places, there were none at all. And it could have been just statistical, and things, you know. But there was no analysis of this. I found the FDA didn't do it, and nobody looked at the deaths.

So this is what I had to conclude about AZT. I mean, I had to satisfy myself as to why I wouldn't use this stuff, and I had to satisfy myself as to – which meant trying to understand why my patients wouldn't have died. What was I doing — or doctors like me, I suppose — what was I doing, or, let's say, doctors in New York, that was different. What's going on?

But what came out of that, really, was an awareness — and this was quite important to me, at the time — although it was pretty obvious, I hadn't, it hadn't sort of

00:35:00 crystalized with such clarity, really, until I looked through these trial documents — there was no treatment for HIV, for AIDS. And if the causes of death were opportunistic infections; then in the short term, at least, whether a patient lived or a patient died could be put down to kind of low-tech doctoring; what I called patient management. Which means how quickly you diagnose an opportunistic infection; how able you are to prevent it, if you can; how skillful you are in treating and diagnosing it, and then treating it.

So all those aspects come into what you might call patient management. And patient management is really old-fashioned doctoring. It's like how you examine your initial patient; how you determine whether they are at risk for this or that, so you are prepared; how you monitor them for different things, and just all the aspects of patient management.

And so, which led me to sort of an appreciation of how neglected this had been. We said we could do nothing for our patients, but we could have done a lot for our patients, if there had been a skillful, compassionate leadership in place.

And then you have to ask where does this leadership come from, and whose responsibility is it? And yeah, let's say the government, in the way of the NIH, or whether it's CDC, have responsibilities, and they, so one could expect it from them. The academic infectious-diseases community, who knew all about these things. There's no formal framework, but they could have gotten themselves together to issue guidelines.

So what we could have done was to articulate patient management strategies; how best to look after your patients, keep them alive, and alleviate their suffering and certainly help them. And we never did this at all. It was always, I remember, it was looking for a drug, a single thing, as if we don't have to do these labor-intensive things —

**SS: I understand your point. But are you saying that the placebo group nationally had worse doctor management –**

JS: Well, I'll come to this in a second. So then, you ask yourself that question. So how is it – if you ask yourself. If patient management can be the single-most, the nature of patient management can be the single most important determinant of life and death in the short term; is there any reason to believe that the placebo group and the treatment group were managed in different ways?

**SS: Um hm.**

JS: And so you'd think, of course not. But, as we discover, the trial — why do we blind trials in clinical medicine, it's really, we all know it's important, but then you have to ask yourself why. Well, we think it's important because we want to know whether an effect we see is a consequence of a drug, but not the consequence of something else.

So bias can operate in many different kinds of ways. And so we don't want the patients to do anything; we don't want the medical people to do anything, in the knowledge that they are going to affect the outcome, and the knowledge that, for example, patients, if they feel they're not getting the drug; because they can taste it — they did this, actually — then they will share the drug with – huh – so that's going to influence the outcome. I'm not saying – who knows how – because people are biased now, because unblinding has led to bias. All right?

So we come to the doctors now. You can't blind AZT. You go through the motions, it's interesting, of blinding. But you can't do it, because AZT, within a few days, leads to changes in routine blood counts that the doctors can see. So they would

know. I could tell you, within four or five days, whether you're taking AZT or placebo. And so we have to assume they knew.

And there are ways you can blind that by – let's say, as an example of how you can do it: I was involved in a trial when – in our early AIDS Medical Foundation, we did some clinical trials. And there was a drug called Isoprinosine, which was nonsense, but we did it anyway. And I was one of the doctors doing it. And it was sponsored by AMF, or AmFAR, in the earliest days. And that to, that drug also changed something in the blood result, which would have given away whether a person was on placebo or drug.

Now that trial was audited by the FDA. And they came to my offices – I was a site, you see, that did this. And they took names, I flew into a panic whether to – it doesn't matter. Anyway, they found a lab report, where this value was visible. So the way that the blinding was done in this case was that the lab reports went to a central place, which happened to be Mathilde Krim.

00:40:00

**SS: Hm.**

JS: Whose job it was to white out the telltale thing, and then photocopy that, and send that to the doctor, so the doctor wouldn't know.

In this case, Mathilde had forgotten to do it, or something. So I was faulted by the – it wasn't my fault, but you know, this was faulted by the FDA auditors as being a kind of black mark. So they knew very well – they could have whited out these things. They didn't. And so the doctors knew. So – that immediately says now: if they doctors know – who's who, are they going to treat their patients differently?

And I remember, Michael is a guy who worked for me, and I explained this to him, and he said, oh, you know, they would have treated them better. Or they would

have been worried, and treated them wor-, they would have treated them more if, they were protected by the drug, and maybe they didn't – so it worked both ways. In other words, if the bias could have led to improved patient management, or it could have led to more-negligent patient management –

**SS: Um hm.**

JS: Doctors might have, oh, the guy's on the drug, we don't have to worry about him so much. Or, who knows?

**SS: Right.**

JS: All we know is that the question remains. So that's it. In any other field, there would have been no doubt about it. In any other field. Anything, any other field.

**SS: I understand.**

JS: It's just like a basic principle of blinding. I wrote this up. I sent it to the New England Journal. They prote-. And not only that. When I wrote up all this I'm telling you now – not in hysterical ways – I've written tons of scientific paper, I know how to do it; and this was quite measured, and whatever. What I did was send it to everybody; I mean, all of the celebrity doctors. I knew many of them, doctors, I just sent it to them. The FDA had it, as well.

Not one word; just silence. New England, just silence, even from New England Journal. So absolute, not a comment, nothing. And it was a very measured thing – simply, at the end of the day saying, amongst other things, there were other there: patient management is the difference between life and death; if patient management could they differ, well it was unblinded, in effect. So the question is open — I'm not saying it

happened. And I ended up by saying, the trial was 12 weeks. And I said at this moment, it would be inadvisable to continue AZT beyond 12 weeks.

That's all. I didn't say stop it, or anything like that. I just said, the question remains.

Now in support of this interpretation is the fact in that mortality differed by site. Now in New York, nobody died.

The thing about New York was that the trial was conducted at St. Luke's, where I used to work myself, so I know exactly where it happened, at Roosevelt. That's exactly where the trial on 58th Street.

But the people who entered the trial — I didn't send anybody — all had a doctor. The study doctor wasn't their doctor.

**SS: Oh, okay.**

JS: They had a doctor. Now in Miami, that wasn't the case.

**SS: Hm.**

JS: Margaret Fischl. The study doctor was the doctor.

**SS: Hm.**

JS: So it's that —

**SS: So there was no uniform protocol.**

JS: No there wasn't. Absolutely no. I said that: there was no uniform patient management thing, no. There wasn't.

**SS: Right, right. I want to ask you a question.**

JS: Yeah.

**SS: Do you think that there was any benefit to AZT if it was only given for 12 weeks?**

JS: Uh – yeah, there may have been a benefit, and I can tell you how that happened. There may have been a benefit. But I'd say it was probably outweighed by the harm it did at that dose. Now it's possible that at a lower dose, you could have retained the benefit without the harm, you know. But they were giving it at something, I think, 1500 milligrams; a ridiculous dose. Which they had, to obviously.

That's interesting, too. When they reduced the dose, they compared people on the high dose and people on the low dose, half the dose; people on the low dose survived greater. And they said, you know what they said? I have, got an email even reproducible. Margaret Fischl said: people on the lower dose survived because they were able to take their drugs. Whereas people on the higher dose found it, they were intolerant of the drugs, and so they didn't take the drugs, and they just went ahead and died of AIDS, because they didn't get the benefit of AZT. They didn't – you can say that.

But in a traditional citing, you've got to open all the possibility, you've got to say, well, it could have been because AZT was toxic, you know. We don't think so, but –

**SS: Well, if it was given at a low dose, for a very short period of time; what exactly would that benefit be?**

00:45:00

JS: Well, I'll tell you one of the things that it did. We did – in, I worked because in the lab — it's another thing that. We happened to have sera from a trial that was done where people were given AZT for one week, and then taken away for a week, and then one week on. That was an ACTG, well they called it ACTU in those days. It happened

in other places as well, this trial. I don't what, maybe they wanted to reduce the toxicity, and thought they could just give it alternate weeks. Monotherapy, in those days.

**SS: Um hm.**

JS: But we were interested in interferon, so in addition to measuring virus, week on, week off; we also measured interferon in the blood. And what we found, and published — with difficulty, but we managed to publish it; it caused me to have a big problem as well, personally — I wrote that paper. When people on AZT for a week, their own interferon just dropped to nothing. When they were off interferon, off AZT, the interferon came back.

**SS: Oh, okay.**

JS: So AZT wiped out the interferon just like that.

Now that's quite an amazing — couldn't get it published — we did publish it eventually — couldn't get it published. We sent it to all the sort of whatever, you know, journals. Never mind the fact that by then — I was the editor of the first AIDS medical journal. I started it, and then I was — you know, had problems with my publisher. But I saw it through its first three years. And it still exists today. But I was no longer — I'd been still with the journal, I would have published it myself. I did publish my own things. I didn't care, you know, because —. Oh yeah, I think I was a pretty good editor there. I mean, I did, I really was good with, I was good, I think. I was better than I've been treated by other editors.

So I arranged, manage to arrange a meeting in 19-, whenever it was, about interferon and AIDS. Because I felt, you know, I was bugged by this paradox: why are

they pumping people full of interferon, and why aren't we exploring the role of interferon in pathogenesis? And so on.

So the Schering company gave me \$25,000. I arranged a two-day meeting in New York. It was quite good. We had international people. It turned out to be quite good. So the two days, dealing both with clinical aspects, mostly with basic science. Had no trouble getting the basic science group. These were my mates, people who certainly knew me, and I knew them, you know. So it was really quite a decent meeting.

I then had the CRI. And unfortunately, you know, as much as I believe in grassroots organizing — I do believe it, absolutely — there are some drawbacks, in the sense that there's some professionalism that's not there, you know. And in any other circumstance, if you had done anything like this and you had papers, you'd publish it, you'd get a book out, you'd get something, you know. Where unfortunately, my friend, once-friend, Marisa, who is the Executive —

**SS: Marisa Cardinale.**

JS: — didn't quite sort of — didn't do, well, she didn't understand, anyway. So at that meeting, we presented this AZT off and on. You know, the interferon-lowering effect of AZT, and suggested that maybe some of the clinical benefit comes from this. And I think that's probably true. All the other antivirals do it, too. But this was the first one. So, some of the benefit, I can't say all of it, obviously, there's a natural anti-HIV effect as well.

But I personally have personally — I share, with many people — now — a view that endogenous interferon plays a role in pathogenesis. And there's tons of reasons to

believe that to be the case. And so anything that removes it probably gives, at least in the short term, some benefit.

But anyway, I did this. Couldn't get it published. And not only that, but another aside: I came up one day to the lab, and I found the commission who supplied the sera for this off and on thing; his resident was sitting with the lab boss, looking at the paper that I had written. I actually wrote the paper. And I came, and I heard him tell her that his boss, the commission, wouldn't be happy with my name on the paper. And I, heh, kind of jaw dropped, you know. And pfft – it was my idea to do the work; because I'd heard that Donna Mildvan – I had heard that she was interested in doing something like this.

00:50:00 And then let's do this as well.

And anyway – the paper did get published. Not the one that we'd submitted; the one that I walked in, when they try to get my name off, but they didn't take it off. But that was rejected, anyway. Maybe because my name was on it; I don't know.

**SS: Um hm.**

JS: But anyway, at the meeting that I'd organized, it was presented. Donna Mildvan, who worked at Beth Israel then, was in the audience. And then our paper say, we had trouble getting it published. And one day, I see in the *Lancet* an article about AZT removing interferon, from Donna Mildvan. Not a word about the thoughts with Dr. Fauci, hero, ends with Dr. Fau-, tribute to Dr. Fauci. You know, pathetic sort of – whatever. And not a word of – she was there, you know. And so I wrote her a filthy letter. And I said, you know, I'm ashamed of you. I really, what kind of scientist, what world do you live in? And of course, I would encounter her from time to time. She always – avoided me, for years and years. Until last year – last, was it last year?, when

the Pasteur Institute put on a disgusting show, because it was the anniversary of François's discovery of HIV — it was 30 years, I think, so it would have been two years ago — and they put on a celebration, you know, and they invited me to go to it, too.

So, anyway, I did go. And Donna Mildvan was there. And one, they had a dinner thing, and at one point, she came up to me, and sort of embraced me. And the first time, after all of these bad, not a word about this. And then she was all, you know – kind of well, I don't know what the hell, so forget it. And then she told me that I, thanked me for taking such good care of her brother-in-law. And then she told me the name of him. And all these years, he was a patient of mine, I never knew that he was related to her. Heh.

So at least we had the chance to make up. So that's AZT. Those are the reasons that –

**SS: Yeah.**

JS: – that I had.

**SS: Okay.**

JS: And it's just never been acknowledged, that's the thing. Amongst all these other things. It's – a horrible trial – that didn't justify the recommendation. And yet, the wider medical community has paid no attention to it.

**SS: Now when did it become clear that people were dying because they were taking AZT?**

JS: I don't think it ever really has been ever acknowledged, actually, to tell you the truth. People were dying, with the AZT, according to Margaret Fischl, because they died of AIDS, they didn't receive the benefit of AZT because of that high dose, they

threw up, and they had bad effects. So they never got the chance of having their life saved by AZT, and died of AIDS. So I don't think it's ever –

**SS: Okay.**

JS: – been acknowledged.

**SS: You don't think it's ever been acknowledged.**

JS: No. Not really. In fact –

**SS: –**

JS: – even if you try and do it – I mean –

**SS: I want to ask you a strange question. If someone is –**

JS: Do you want some more something?

**SS: I'm fine. Do you need something?**

JS: No, I don't.

**SS: Okay. If somebody is infected with HIV today, what do you think they should do?**

JS: Oh. They need a good doctor, I think, to monitor them. And what I would do now if I was still around, at the moment, I would – it depends where they are, you know. If they're diagnosed with HIV with two T-cells, that's one thing; if they're diagnosed – I have to say quite clear – not one size fits all. But you'd have to say –

**SS: All right, well let's say we're in London, and a person has just been infected. They're newly infected.**

JS: Just been infected.

**SS: Yes.**

JS: If they've just been infected, like now –

**SS: Um hm.**

JS: – I'd put them on treatment. Absolutely.

**SS: What treatment would you put them on?**

JS: I'd put them on, I don't know at this moment; but I'd put them on something really –

**SS: Like quad, or something like that.**

JS: Yeah, something effective. I'd also probably be interested in doing – but I would definitely put them on treatment. If it was a year afterwards, or, I don't know, that's a bit fuzzy to me, because I think it's undoubtedly true that if you get people really at the early, you might be able to put them in a way, well, you might even be able to stop treatment for a long period. But if you catch it that period, or you might be able to treat them before things are established, you know, have taken hold, in terms of the size of the amount of latent virus, and you might be able to and there's enough evidence I think it's a good idea, and even start with some support that notion.

How long afterwards – like six months, I don't know. But if it's say, more than a year, I might – it depends on where their T-cells were. I just wouldn't jump to treatment.

**SS: Okay. I have one big question I want to ask you, and then after that, it's whatever you want to tell me.**

JS: Alright.

**SS: So you're very, very well-known for being one of the people who invented safe sex, right? That's one of the many things that you're known for. And we know that there's only a certain percentage of people that are able to negotiate condoms, ultimately. And that no matter how much information is out there, no**

**matter how many campaigns, there's a significant percentage of people who will not or cannot negotiate condoms.**

**So on some level, safe sex has been highly beneficial for only a certain group of people.**

JS: Well –

**SS: And nothing is changing that. Okay, go ahead.**

JS: Well, when you say “highly beneficial,” there's more than just simply people. There are sort of community issues. It's been highly successful in stopping the epidemic, actually –

**SS: That's right.**

JS: – the growth of the epidemic.

**SS: That's right.**

JS: So it's more than just a handful of people.

**SS: No, I didn't say “handful.”**

JS: It's more –

**SS: No, I said it's totally paradigm-changing. And yet, there is a persistent percentage of people who are never able to do it.**

JS: Okay. But there's a difference between a population and people.

**SS: Right.**

JS: So already, we have to look at it in a rather different kind of way. If condom use in the early 198- and mid-1980s is what turned it around, it's what stopped –

**SS: Yes.**

JS: – the further spread; so that meant it made the world safer for everybody else. So that's a huge achievement, already.

**SS: Yes. It is.**

JS: So I hope that will be maintained. And there's a chance that it's not going to be maintained. So if – I think I know what you're getting at. If there are a handful of people — which there are some people, around a handful, who knows how many, who won't use condoms — then your question is, what about – what's the question?

**SS: I'm interested in why, persistently –**

**SM: I'm sorry – we're going to have to change the battery.**

**SS: Oh, we're going to change the battery. Okay, let's just take a break for a sec –**

**Ready? Let me start again. So you're one of the founders of safe sex; something that has saved millions of people's lives, and completely transformed the epidemic. And yet, there's always been a small percentage of people who cannot do safe sex, for a variety of reasons. What are those reasons?**

JS: I think there must be a multitude of reasons. I'm not going to assume. Well, it depends on – when you ask, well, why people don't – well –

Alright, I think – this is just conjecture here.

**SS: Uh huh.**

JS: Because none of it seems totally reasonable, and it's not completely – it depends on your positioning in the sexual act, for a start. If you are a bottom, for example; what's of interest to you is whether your partner uses a condom or not. So it's a different thing going on, over there that, who is using the condom. But it's an important

part – so far, we like to think of as being consensual and so there is a factor. If you're the penetration, you're the – then it's obvious that some people may have erectile problems with condoms. I think this is probably more true as people age. As men age, it becomes a little more difficult to maintain erections.

This is all kind of reasonable conjecture, right.

Then there is, some people may claim that in terms of the sensation of sex, this is where condoms constitute a barrier. But that's also very variable; and also, I think, it depends on just how old you are, in a way. I imagine an adolescent probably couldn't care less, in terms of – the vigor of the – as his sexual response becomes –

So it goes with where you are in your life, and how old you are, and what it is you're doing.

I've heard people who are receptive partners in sex who say that condoms interfere with intimacy; but for the life of me, I can't understand what that means. Heh. I mean, I've asked enough people who say you can't even tell the difference, in how they feel. So it's a psychological thing presumably.

**SS: Okay.**

01:00:00

JS: All right? There are, how can I put it, I would say, of all the range of objections that one can imagine, I think there are those that one – I don't like to say the word "legitimate" — but something like there are those which are sort of understandable, and those which may be idiosyncratic, as it were.

But –

**SS: But there's been a cultural turn against safe sex.**

JS: There's been a cultural turn against safe sex? No. I don't know that's really true. I mean, if you read things, if you're a Facebook person; if you read certain magazines and you read things, and you say, this is a cultural change. But amongst who? I don't know – the vast – people don't necessarily have a voice. Those who have a voice are just talking about themselves, and their particular little group of people, so I don't know how you can extrapolate from that to the larger, let's say, a cultural change, it's an all-embracing kind of thing. And I don't know. Quite often, people on the ground who don't have a voice are more sensible than we give them credit for. You know, they just don't have a voice, they don't write everything on a journal or in a newspaper, earlier. They're inarticulate, and just get on with their lives, and sometimes in a more sensible way, maybe, than we give them credit for.

So I don't know if that's really true, about there being a culture against safe sex, other than amongst certain circumscribed kind of cultural units, as it were, maybe.

**SS: Yeah, but we're in a very strange period, where there's HIV criminalization –**

JS: Yeah. Well –

**SS: – there's enormous stigma;**

JS: Well, there's always –

**SS: – people with HIV have no voice in the culture;**

JS: People with HIV –

**SS: – they're much more in the closet about being HIV-positive than they were –**

JS: How do we know? I don't know if that's true. I might have thought just the opposite about being – I think HIV is – think about 1983 and '84; where people's certain with respect to their sexual orientation itself, it's a different universe now, for many people. And maybe not in Bangladesh, but here. And –

**SS: So why are we seeing such high infection rates?**

JS: We're not, really. We're seeing high infection rates in circumscribed populations. It's not across the board, as far as I know. It's in very –

**SS: Well so in London there's –**

JS: Not just London. It's in a certain age group, a certain – it's in a certain demographic. It's not across the board. And in fact, across the board, I'd say we're doing very well. Across the board –

**SS: So who do you see as the people who are being infected now?**

JS: As much as one can get it from the cloud, or what one comes across, is that there about 5,000 new cases in the UK. Now how does the breakdown, Simon? Those that are not in immigrant communities would be what, how does that break down? Now, I don't –

SW: I don't have the exact proportion in my head. But that 5,000 has to be put against the total population of whatever we are now – around 60 million?

JS: 65 million.

SW: 65 million, which is about a quarter of the United States, it would be the equivalent of the United States having 20,000 new cases a year. Which would be taken as tiny when we asked them.

JS: But where are these cases distributed? It's not across the board.

SW: The cases amongst Black Africans have gone down markedly consistently over the last 10 years, which is incredibly hopeful and good news. Generally, new cases amongst Africans resident in Britain, visitors and long-stayers here have gone down. So it's infection both in Africa and in the UK, it seems. But gay men, but it's demographic that Joe is coming to talk about now; young men, on the gay scene, many of whom are visitors to London for the first time –

JS: Yeah. It's sort of culture of –

SW: – immigrants, refugees, a huge number of refugees who are sex workers get involved in enormously powerful drugs, that weren't available even 10 years ago.

JS: It's circumstance, it's about the, apparently is circumstantial. Hm.

SW: – There's this kind of pond in the middle, drawing new people into it, certainly, and feeding out.

JS: Can't – so I think –

SW: So mainly it's all caused by itself.

JS: It's ominous, you know, in a way. I mean, I'm not a – I know there's a whole sort of culture of sexual, queer things. I know nothing of that literature. But just from a common-sense point of view –

**SS: Um hm.**

JS: I have sort of thought of things in terms of a, what you might call a sexual space; and it's where people have sex who are — and for many people have single partners, and it's not an issue. I mean, their sexual space is protected, it's fine, and all of this. But for people who are not regularly attached, they have to have sex, if they're going to have it, generally they will more or less, frequently, infrequently, enter the

sexual space, and have, one can say, how from an inspection point of view. And not just with HIV.

That's another ominous thing, is the sort of denigration, if you like, or the minimization of other sexually transmitted diseases as if they're just kind of nothing, you know, which is completely ominous, too. That part is scary.

So how dangerous is the sexual space, where you go to have sex? You know, where you go off to have sex. And so is it dangerous, not dangerous?

So that's a sort of population thing that one also has to think about. And so even if things are concentrated, now; I don't think we can sort of say they're going to remain concentrated in that kind of way, because I know people who have become infected within this sort of say, can't safe, or whatever, this highly – drug-using; sort of rather intense milieu, that involves probably people between the ages of sort of 17 and 30, only maybe, I think, mostly, you know. They're just – and that's been the case in New York, too. All the new cases have generally been predominantly younger people, even adolescents. So it is a select demographic, for whatever reasons.

But one can't say that this is going to remain confined here. Because these people will go out, and – that there won't be so many of them, you know, so the risk, if you put it, of having an anonymous sexual encounter – you'll probably be perfectly, from the HIV point of view, perfectly safe. Now to say one in 10, you're going to meet somebody with, you know. But that might gradually – the problem is that that might gradually increase. And so that even – it will spill out of that confined thing. But I hope that's not going to happen.

But the fact is that it appears to be pretty concentrated here. And so if one wants to be helpful here, one should really focus on that population. Give them more PrEP, I suppose; that would be an answer. But it's not going to happen. And if it were to happen, the only way it could happen would be for communities themselves to take it up themselves, and just not wait for the governments and HSEs. This is what I've been saying the whole time: just raise some money and buy them fucking drugs, you know.

**SS: Right. So you think that PrEP should be widely available.**

JS: Not widely, no. I mean, look where the action is, and protect these people. But it's not very attractive. I mean, these are guys who are damaging themselves. I mean, it's hard to drum up sympathy for some –

**SS: Because if everyone who is — this is a naive question — but if everyone who is infected had the proper medication and was virally suppressed, and therefore not infectious;**

JS: Yeah.

**SS: – why would you need PrEP?**

JS: If everybody, heh heh – yeah, but if everybody, that's a sort of a – forgive me –

**SS: But the PrEP is a – it's a reform on the problem of people not getting their meds that they need, right?**

JS: Uh – no, I don't think – I mean – put another way, the situation you describe, of everybody being on the meds, is an idealistic, unattainable pipe dream. It's just not real.

**SS: And why is it unattainable?**

JS: Because the logistics and the culture involved in doing this, and the finance, are just simply not within reach. It isn't.

**SS: Because the state won't pay for it. But if they would pay for it –**

JS: But even so: people are not compliant –

**SS: People are not compliant.**

JS: – human beings are human beings. It's just –

**SS: Right.**

JS: – not practical. And the same –

**SS: So the –**

JS: – same thing goes for PrEP, too.

**SS: Right.**

JS: So, you know.

**SS: So there's always going to be some transmission –**

JS: Of course.

**SS: – because human beings are human beings.**

JS: Right, so?-

**SS: All right. So we're looking at a future –**

JS: We do what we can, you know –

**SS: Right.**

JS: – we're going to –

**SS: Okay, so if there was to be the eradication of HIV disease, what do you think is the right path towards that?**

JS: Eradication of HIV disease?

**SS: Yeah.**

JS: I think it rather differs. If we're talking about Africa, if we're talking about – where are we talking about – it has to be different –

**SS: Let's say London.**

JS: Eradication of HIV disease here in London.

Complete, I don't know whether that can really be achieved, but it can be, I imagine, much diminished. And I think one of the – it would have to be something that involved many components, not just simply by medical part of it, but also behavioral. I could imagine –

**SS: Is there such a thing as a cure?**

JS: No –

**SS: No.**

JS: – it's bullshit, it's PR rubbish.

**SS: That's PR rubbish, okay.**

01:10:00 JS: It always was. I do recall – if you could cure HIV, you could cure cancer. I don't know – you know, eh – the chances are – I mean, if they're doing, the technology involved in genetic manipulation – at least, you know some approaches — would be such that if we could do that, we could do inherited diseases – we would do all sorts of things. It's just –

I recall, round about 2000 or something like this, when I was still in New York, Sean Strub sent me something from somebody in Philadelphia, I can't remember — it was a woman — who, we've got to get behind a cure! And was totally uninformed, medically speaking. And I sort of told him this. Kind of found it attractive. And other

people – so I think it was a movement that sort of took root in, let's say, uneducated scientific — I don't mean that as a putdown —

**SS: I understand.**

JS: – simply fact, eh? You know, from people who don't know what's involved in this, and just have this sort of arrogant – sort of, we cure it, let's cure it, you know. And it started that way. And then the scientists took it up. That's a good fundraising thing, so, you know, AmFAR has what they call “cures.” Cure research. And people now actually believe it now, but it's a hook to sort of raise money. So, okay, all right –

**SS: Well, what about vaccine? Is that a possibility?**

JS: – I think there will one day be, there will be vaccines, I imagine, sure. Not tomorrow, but I believe – in principle, there's no reason why – it's difficulties, but I can't see why it shouldn't eventually be actually overcome.

**SS: So those are all my questions. Do you have anything that you think –**

JS: Probably a million things –

**SS: A million things. Is there anything really big that you would like to talk about that –**

JS: I don't know. What do you think people might – I don't know –

**SS: That you want to make record about?**

JS: Oh. Being probably judicious, I don't want to provoke anything bad.

Well, I haven't had have very good community relations, as it were, in New York.

**SS: Why is that?**

JS: Well there's something, I suppose. I don't know why. I mean I can certainly guess, of course. Don't know why that's been a little unpleasant for me, because I really

try to be helpful. I can't believe I've been motivated by anything, really, else. You know, I don't have any, heh –

**SS: In those days, a lot of people were yelling at each other and mad at each other and mean. Now there's like a lot of that is over.**

JS: Because the ones who yelled loudest have silenced everybody else, and now they – now they yell at each other. But they've been singing the same song, so I suppose they, there's nothing – I mean, I'm frightened to open my mouth on certain things, too, because they're so mean and nasty. I don't think that's stopped, necessarily. And I've seen over these PrEP things, completely kind of childish, hysterical kind of un-thought-out, stupid stuff. So I'm afraid the propensity to be mean and nasty is still very much with us.

**SS: Well, one of the things I've noticed is that, I mean, you and I are different generations but we're the same AIDS generation. And within our generation, we all care about each other very much, even the people that we hate. The people who we hate are very important to us. Other people don't give a shit about any of us. We're all involved with our dynamics with each other. And we don't let each go. There's an emotional attachment; even if it's negative.**

JS: Ah! Uh –

**SS: It's true.**

JS: Well, I, I, I –

**SS: Because we've had a specific experience, and everyone younger than us hasn't had that experience.**

JS: Well, I don't know, I should rather feel rather differently, actually.

**SS: Tell me.**

JS: I feel rather di-, I mean, I – there are those who, I would agree, and I have such relations with. But there are others I feel have – taken sides, if you like, and taken positions that I feel have not been all that helpful, actually. So – and personally me, I've been impeded in so many different ways. And I believe I could have, you know, had been more use, in a way. It's not that the ones still loves those people who –

**SS: No, of course not.**

01:15:00 JS: I mean, the organizations I've started, almost the thing, have all been taken away from me – in most unpleasant ways – and turned into, really, turned into things I'm sorry that's what they've become. And I can't feel any love for, heh – for the forces and the individuals who were instrumental in, I suppose, perverting or changing or whatever, those initiatives that I was very much involved with setting up.

**SS: Right.**

JS: Can't feel good about that.

**SS: But I mean, do you ever look at it philosophically? I mean, people who are a little bit ahead of their time do very well. But people who are very, very far ahead of their time are often vilified. This is historically consistent in every field.**

JS: Yeah, I know. I kind of think I can appreciate that. But how is that supposed to be helpful?

**SS: I mean, just to see it beyond the phenomena of their own experience.**

JS: I think I can do that. It's still not very helpful to do that. It makes it –

**SS: Yeah.**

JS: – even worse, in a way. Heh!

**SS: But what would be helpful?**

JS: I don't think there's – I'm not in need of help. That's not –

**SS: Okay.**

JS: – it's not where things are at. It's just, at the end of the day, you watch things, and it's a mix of sadness and – yeah, just sort of sadness about – I can't, and I feel there's nothing you can do with that.

**SS: Yeah.**

JS: I'm very sad, for example, sad — I don't know, I can't find the right word — but if I think of the people in the earliest years, the patients who, or people with AIDS, who died horribly, and who did, I think, rather wonderful things on this Earth, who completely just don't exist any longer. They've been – the things, some of the things they have done, the credit's been taken by others. They're just forgotten. And the – not that one needs to memorialize individuals, but – at the end of the day, maybe it's just sort of the sadness that sort of kind of ineffable suffering is for nothing, in a way.

**SS: Um hm.**

JS: And maybe that's the sort of sad lesson –

**SS: Yes.**

JS: – it's nothing, you can't jump for joy over that.

**SS: That's right.**

JS: We don't advance, we are not a whole lot better, and – and in fact, there's nothing to, it's not just simply HIV. It's just, look where we are today, and the world sort of –

You know, I'm old enough to know the Second World War. I was alive during the Second World War. I was – at the end of the war, I was probably – 15, 14 – enough to remember the realities, and certainly was kind of close enough. I mean, I was not unaware that if my father and mother hadn't made that trip — heh — I would not, you know, what would have happened to me. So –

**SS: Right.**

JS: It's theoretical, right, but it's very real, because there were people whose families, there were actual individuals, there were pictures, it was kind of like, there.

So in a kind of sad way, I think only people of my generation, or people the generation ahead who feel something like the Second World War was a watershed moment in my history — not in anybody else's — I don't mean mine, but –

**SS: Yeah.**

JS: – my age group; it was unlike other – not necessarily it was really so, but unlike other – wars; the Second World War could be seen, legitimately or not, as an ultimate fight between good and evil. I mean, it was so in-your-face. I mean, Nazis, bad; gas ovens; killing civilians. Just monsters, on the one hand; and here we are, on the other hand.

So if we saved the world from – if the body-snatcher sort of thing. It was a – symbolic, it was. A lot of things that I understand that were rather wonderful things came out of the Second World War, starting with the Universal Declaration of Human Rights, for example, which I think is a wonderfully – it's a great document. Or the medical ethics that didn't exist before came from the Nuremberg trials, the Nuremberg code.

Research et-, I mean a whole – dominated by the thought of Never Again, this will never, ever happen again. It was absolutely real. After what Germany looked like in 1948.

Even in 19-, my father took me to Europe when I was 15; and that was 1948. And he had been there just two years or so before, in the army. And had his friends. And I met them, you know, partisans, people. And I was only a kid. So it was absolutely real. And he left me at school there.

And in '48, there were no lights in Rome. The buses were covered wagons and trucks. At least I had a taste of some of this.

And so it was, as I say, the Second World War was a – a watershed moment, in the sense of – let's say, good and evil, and things were set up in order to protect us from this never happening again.

01:20:00 Well, and so you can imagine, for people of my, roundabout then; 50 years later, 60 years later; we're back to where we were.

And so for people who, let's say, two – intergenerational memory just is no good. We do what we can to forget.

New York is a good example. After 9/11, for two days, you saw photographs of people plunging out of windows. And then they wouldn't let you see that anymore. You've got, oh, we can see blue lights. For Christ's sake; I mean, you know, we've protected from the memories of bad things – for some who-knows-what reason. But this is a sort of culture – blue light, for god's sake.

So this still may be part of our psyches, and we just sort of try and protect ourselves. But we –

So that was just a sort of a little bit of an example. But this forgetting is – I understand it intergenerationally. But for people who were kind of around, certainly of my father’s generation, who was very much part of where there’s a certain hopelessness, you know, to see ourselves back, as it were. That impact is never again – just unthinkable, is actually on the verge of, it’s happening already. And so it sort of deprives one of –

**SS: Yes, but all we can say is that, look; millions of people are alive because of you. It’s a fact –**

JS: Oh.

**SS: – and other people like you. But people like you are not the majority of the kinds of people in the world. And so there’s this constant dynamic between the kind of people that you were naming before; who are greedy, who are limited, who don’t care, who are narcissists, whatever –**

JS: Yeah, but the consequences – somehow – I don’t know – yeah, what can one say – it’s – the notion of social concern – here’s what I have discovered to do with PrEP. I think I’ve discovered. And – the arguments about PrEP which – kind of withdraw from, because it’s just hopeless. The polarization. I don’t – and it’s interesting to see why PrEP, why has it been such a vivid and in-your-face argument. Why? What is there about it? It must be kind of complex. But it’s certainly tantalizing to try and sort of get to the bottom of it.

**SS: Um hm.**

JS: Both from people who are HIV-themselves-infected, and those who are not. And any objection or any reservation one might have had, I’ve had, about PrEP; I’ve seen

how the response has been so polarized into you're either for PrEP or you're against PrEP. There's no, nothing in between there.

And so if you have reservations, say, about implementation; you're against PrEP; somehow you have to deal with a shrill kind of back-and-forth. And it's awfully sad to me, to see. This is kind of like truncating your own possibility of being intelligent, and being proud of being stupid, by refusing to look at nuanced things; everything is can only be dealt with if it's black and white. And that's why discussion is so putridly uninteresting, actually. You can't get in any sort of, you know.

And so I have thought – but in trying to work this out, I've come to some sort of rather – unpleasant realization.

And I had a – a message from somebody who's written an article about PrEP – in the last few days. And he asked me to read his article. And it's not a good article. And it's puerile, you know.

What he is doing is speaking about his own personal experience. And he is saying, well, I'm HIV-infected, and I was on PrEP. And it turns out that he wasn't HIV-infected. And PrEP worked, and it's all a big sort of trumpet call; everybody should be on PrEP, you know. And then on and on about take – And also about condoms: I don't like condoms. It gets in the way of intimacy. I thought, oh, thinking.

And I thought, how am I going to get through to this – is there a way in which I can get him to listen to – issues that are relevant to PrEP, and have nothing to do with whether PrEP's good or PrEP's bad, you know.

So I thought of something; and I got a response from him, which has been somewhat illuminating.

01:25:00

I said to him, I said: you have told an engaging story, a personal story about yourself, about your choices. That's fine, you know. I said, but now for a second, try and imagine yourself as being responsible for other people. You are now the director of public health. And you're making decisions on behalf of a population of people. And you know that in that population, there are adolescents, there are people who are irresponsible, people who don't care about their health very much. You know, there are all kinds of people. And there are responsible people, they're just people. Some are not terribly bright, some are bent. Whatever; it's a population. And having to make decisions and recommendations on behalf of others, what would you do?

And I thought maybe if he looked at it that way, he might actually see this. There are issues about implementation; about adherence issues; all sorts of, you know, other sexually transmitted disease.

And he had told me that he goes to the doctor every four months; and he gets checked for things. And I mentioned – so you're now the public-health director, and you're making decisions for people. Few of them have doctors they can go to every four months. Some of them don't have any doctors at all, and they have to go to some crappy clinic, and they probably won't do it.

So you have to think about those people, too. You're deciding for them.

And his answer was that as far as, he was very firm, as far as he is concerned, if people have information, that's the extent of my obligation to them.

So – and I realized that there are so many people who feel just that. They're, just that. And that goes back –

In 1981, when I was looking after another gay men in the epidemic, the beginning, even before that, when New York was a – the patients I had were kind of, you know, The Saint, Fire Island; they were, you know, kind of – syphilis every five minutes, whatever.

**SS: Yeah.**

JS: But those were the people I was seeing. And I would come across people who would go out to the bathhouse and have sex when they knew they were infectious. And – I would talk, I'd talk to people about it, you know. And that came up with the same answer. And they said, well – people know what they are into, and –

**SS: Yeah yeah.**

JS: – taking their chances. So there is this thing. And then I relate this, maybe, to sort of individuals in America, the lack of social – the extent of my obligation to you is just to let you know information, and if you choose to – it's always your choice, as if people are free to make a choice.

**SS: You know, Joe: I want to say something to you, and we need to end. But I want to end, I want to say something to you. Because you're, how old are you? You're 82 years old. And you've done all these incredible things in the world, and you've made the world a better place with –**

JS: Eh –

**SS: – your life, you have. But you haven't figured out that there's not a lot of people like you. You're an exception. And if you can't accept that, it's going to cause you a lot of misery.**

JS: Well, I don't have much time to be miserable –

**SS: But seriously, that's the burden of special people, is that they can't understand why other people don't get it. I mean, it's –**

JS: Well, are you sure? I don't know, I like –

**SS: Yeah.**

JS: – to think that it's not so, you know, that –

**SS: Not everyone can be as responsible as you, not everyone can be as imaginative as you.**

JS: It's not a great leapt to have this, to have bit of, a bit of –

**SS: Bubbeleh –**

JS: – even from the –

**SS: – you're special.**

JS: Oh come on, I mean –

**SS: I'm serious!**

JS: I mean, look –

**SS: I know you're deflecting it. But that's the source of a lot of your unhappiness.**

JS: But having, a little concern for – in a more social kind of way, is actually having concern for yourself. Because one of things –

**SS: Right.**

JS: – take sex, for example. If you are just sort of very cavalier about others, and your attitude is, well, it's on their head, they're going to get sick, and it's their business. But the fact is, they are infectious. And it'll come back to bite you.

**SS: I understand.**

JS: You know, so you're really pursuing your own self-interest.

**SS: We have to end.**

JS: Okay.

**SS: Thank you.**

JS: Pleasure.

**SS: It's really been an honor. Thank you so much.**

JS: Okay –

**SS: I'm s-, yeah.**

JS: I don't know, a lot of time must have passed.

**SS: Yes, we've been here for three and a half hours.**

JS: Can I give you –