

AAHP
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Interviewee:	Janet Conners
Interviewers:	Alexis Shotwell & Gary Kinsman
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Persons present: Janet Conners – JC
Alexis Shotwell – AS
Gary Kinsman – GK

[START OF TRANSCRIPT]

AS: So, the first thing that we say is where we are, which is in Annapolis Royal, Nova Scotia, and it's July 22nd, 2016.

GK: So, where we start every interview is just to talk to people about what their first memories are with hearing about AIDS – what did you hear?

JC: You know, I think the first time I heard anything about AIDS, it was 1978 or 1979, and I was living in British Columbia. I think I was pregnant, and I was waiting to see my doctor, and there was a *People Magazine* in the waiting room. I picked it up, and there was an article about a man who, at that time, was identified as a drag queen, and he had this strange rash that they thought might be herpes or, you know, I'm guessing now it probably was Kaposi's [Sarcoma]. The whole interview, the whole story kind of was focused on him, and just little threads of this "weird thing in San Francisco," and "this weird illness from someone in Minnesota," and things like that. And you know, I'm not even sure that they identified it even as GRID [Gay Related Immune Deficiency]. I don't know how much I remember from the article that was, "Oh yeah, that was an article about AIDS," or as time went on that I started to really clue in.

Then the next time was, when I came to Nova Scotia, I got a job in the microbiology lab at the VGH [Victoria General Hospital in Halifax]. One of the sub-labs in that lab developed the first Canadian HIV test. Of course, because it was a microbiology lab we handled all of the infectious samples... people who were having any blood work, or anything for TB [tuberculosis] or anything like that, it all came to our lab. So, I'm guessing HIV had been identified, but we just had a series of safety lectures within our department on precautions that we needed to take from now on. You know, even at the time, I was with Randy, and it still didn't click in that I was at any risk. Because, of course, by then anything that *was* being said publicly was that it was gay men. And hemophiliacs had been told for quite some time, "Oh yes, well, hemophiliacs are getting this thing from the blood, but they're just carriers. They're not developing the disease. It's just like they have Hepatitis A and B, and non-A and non-B, but they're just carriers!" So, even knowing that Randy was HIV positive at the time, it still didn't really sink in that I was at any risk. Because so much education or information was homophobic and focused on the gay community, and "bad, bad, bad!" And conversely, hemophiliacs by and large were still being referred to as boys. In the clinic Randy went to, the hemophilia nurse would talk about "my boys" and I would say, "But he's in his thirties and he's married! Like, he's not really a boy anymore!" So, there was that thinking, as though they weren't really sexual or something.

GK: So, the question we'd started with was just—

JC: Where did I first hear about it. I think that view, it sort of extended to us as well, to the wives or sex partners or girlfriends, that we were really just their caregivers; we were sort of extensions of their mothers. Certainly, I would say, that was the feeling in Nova Scotia. I would get scolded often by the client care. At first the hemophiliacs didn't go to the HIV clinic. They went to the hemophilia clinic for treatment of HIV. And there was an expectation that as the wives, the partners became positive that we would go there as well. It was this whole very bizarre, "We have to protect them..." And through the hemophiliac clinic, anytime the discussion would come up about blood supply, it would be, "Well, 10% of the blood comes from gay men." So, it was this constant, subtle message that we should blame gay men, you know, to really keep the groups divided.

I mean, really, I had sort of a fight on my hands from the establishment when I said that I was going to go the AIDS Coalition and see what's what there. And, "Oh, there's no place for you there! You'll never be welcomed!" When I went in, Robert Allan was, I don't know, the executive director, or whatever his title was...

GK: You're talking about the PWA [Persons with AIDS] Coalition.

JC: The PWA Coalition, yes. I did go to AIDS Nova Scotia, and I'll talk about that in a bit. But I went to the PWA Coalition and I spoke with James Shedden, who was working as a volunteer. He was a receptionist at that time, and he sort of showed me around. And then immediately ushered me into Robert's office, and I'm thinking, "Oh my god, I'm like, seeing the king of AIDS or something! I don't get this!" And what it was is Robert, you know, to his credit, was a really good community builder. Immediately he's like, "Oh my god, somebody from the blood community? Great!" And within a very short time, both Randy and I were on the board, learning our way as we went, on the board. I'd never sat on the board of anything! But that was the excitement, that someone from the blood community was there. It was the exact opposite of what I'd been told, in terms of that we wouldn't be welcomed, and that there would be no place—now, that sentiment did exist, and I did have that said to me many times over the years, but you know... I had attended a retreat in Fredericton, and I drove up with Father Mike McDonald. And one of the things that they said at this retreat, Glenn Pelletier, from I think Guelph, was facilitating the workshop. And one of the things he said to us is, "AIDS service organizations belong to *you*. So, go get them. Go take them back." At that point I didn't even really know what an AIDS service organization [ASO] was. I think I'd heard of AIDS Nova Scotia, but certainly not the Coalition. So, I just jumped in with both feet.

AS: Had you been an activist before that?

JC: No. But, you know, I'm a middle child – middle of six – so you kind of are an activist! "Hey, I need some food!" [laughter] You kind of have to lobby for your own survival! And as a kid of the '50s... my parents, they were very traditional in a lot of ways. My father was a prison guard. So, people were like, "Oh my god, you grew up with a prison guard for a father!" But you know, I was nine years old when my father sat me down and told me stories about some of the men that he worked with. And that's how he felt about them, that he worked with them. I don't know why, I was eight or nine years old, and he explained to me that there are men, that when they're in jail, they love – is the word he used – they love other men. But then when they get out of jail they love

their wives again. He gave me this whole explanation. I think I'm the only one out of the six kids. And he talked about men in jail who really tried to get women's clothes, and liked to wear women's clothes. Back then I think I was eight. It was 1962 that my dad sat me down – or '65, something like that – and he had that conversation with me. So, they were really forward thinking. You know, we were raised in a church, we were raised as Anglicans, but every Sunday that they were able to, they would take us to—you know, we lived in the Lower Mainlands in BC, so we were in synagogues and we were in mosques and we were in monasteries and we were in churches of other faiths. It was just a really different upbringing for the '50s and '60s. Especially when you think, you know, we were kind of with the prison crowd, you know? That's not usually who you'd think prison guards are. So you know, if they were starting a family today, my mother would work and my dad would stay at home and cook, and do what we think of as traditional female roles. So, I think that probably had something to do with it. We kind of grew up with different values. I mean, my father was a way better cook. We would have starved to death if we had to rely on our mother! [laughter] You know, I remember my dad taught me how to iron. But my mother won axe throwing competitions at county fairs and things like that. So, I think that kind of is where it came from. But also, just that sort of good, prairie depression work ethic, where... I always still, to this day, feel embarrassed to call myself an activist. To me, and I've used this analogy before, it's like there was a pile of dirty dishes after a party, and somebody had to do them, so I rolled up my sleeves because I'm really good at washing dishes. And I stumbled upon the fact that I speak pretty well, and that I can be and do the work of an activist pretty well. That's kind of what it was for me, it just was something I figured out I could do.

AS: And did it feel different? You were talking about that kind of quality of paternalism from the medical establishment to the hemophiliac community. Was there also a different energy in the PWA Coalition?

JC: You know, when I first went to AIDS Nova Scotia, I went to a volunteer orientation. When I would talk about it a little bit at clinic, that's sort of where they'd steer me, and same with the hemophilia clinic. Like, "If you're going to go anywhere, go to AIDS Nova Scotia." Which I think was viewed as calmer and not so radical or activist. And for someone like me, what they thought of as an "innocent victim," that would be the safer, better place for me to go. So I went to a volunteer orientation and I sat through the whole thing, and said to the person who was coordinating it, "So, I'd really like to volunteer." And she said to me, "Oh well, I'm sorry, I really don't have time to teach you AIDS 101, or teach you about HIV prevention, so you can volunteer to do the work." So, sorry not interested. I'm saying, "I'm pretty sure I probably know more about AIDS than you do, since you don't actually have it!" [laughter] So yeah, pretty quickly I found out, "No, this is not the place for me." You know, I kind of was back and forth. I took my mother to a support group, a family support group that existed there, and that was very bad. Oh yes. It was very bad. We'd just disclosed to my parents. You know, I thought this would be with other mothers, and my mother was of a generation where she doesn't really talk about those things in public. But she was wanting information. And, I think, wanting to try to meet other women her own age. So, somebody dragged out quilt panels, and it was just the absolute *worst* information that they could've given her. It was just all gloom and doom, and "Oh, but you know, you can make her a quilt panel after she dies." It was just really awful. And, what was her name? A sister from Boston, and she I think taught at the Mount... she was fabulous. It happened that she wasn't there that night, so somebody

else in the group was facilitating. My mother never went back. I had a somewhat difficult time with being associated with any AIDS service organizations because of that first experience.

GK: So maybe just to step back for a moment, and then we'll come back to the PWA Coalition, but you sort of mentioned a little bit about how you became aware that Randy was HIV positive. So maybe just tell us a little bit more about how that took place for you. You talked about how, even when you first heard that, you didn't think that meant anything for you. But how all that begins to change, that you find out you're HIV positive as well?

JC: So, Tom Brokaw did a programme, a special, called "AIDS in America" in, I think 1985. And I watched it. I was still interested, you know, I was working in microbiology, and things were happening there. He gave a statistic about the number of hemophiliacs who were infected, or seemingly infected. Randy was a hemophiliac, and a severe hemophiliac. We were just dating then. So the next time, that weekend that I saw him, I said, "Oh, you know..." I explained I had seen the show, and he said, "Oh yeah, I've been tested for it. I don't have it, and if I do I'm just a carrier. We don't need to worry about it." A lot of hemophiliacs were told that, that they were tested for it, before testing even existed. I remember he pulled out a letter and showed it to me from a clinic in New Brunswick, and said, "Oh, ha ha! Look! I'm certified to not have it!" I said, "Well, you know, let's just go." So, we went to see my family doctor a couple of days later and we were tested, and my doctor said, you know, "Probably, Randy, you are going to be positive. And Janet, you probably aren't, because women aren't getting this disease." A week or ten days later or whatever, my doctor just called to talk. And Randy's getting ready to go to work, or go to school, and he said, "Well it's what I expected. Randy's positive and you're not. There's an appointment at the HIV clinic for Randy." That's how we found out that he was positive. So, he went to work, and I did my thing, and then... I'm trying to remember. I don't think I went to his first appointment at the clinic with him. But right from the start we were being told to just use condoms if we wanted, that they weren't seeing the disease being passed to women or sex partners of hemophiliacs. We chose to use them. But there just was not a whole lot of information directed at me that I was at risk. Or even when I'd say, "You know, it seems like a lot of the condoms are breaking." I grew up in the age of the pill, so I'd never used a condom in my life until we found out Randy was positive. We didn't even know how to use them properly. Nobody thought to teach us. Then eventually I would just go to my family doctor to get tested. I was tested every three months, then every four months, over a period of three years or so. I mean, we did use condoms every time. But I'd say over 30% of them broke. Yeah. I mean, we weren't buying cheap condoms, but we weren't using extra lube. I mean, I don't think we were doing anything that much different than any other couples do. But a lot of them broke. In those days they were telling any person with a fluid receptor to douche. Which you know, it's a vinegar and water douche, which was, as we now know, exactly the wrong thing.

I think mostly I was just viewed through that time as this caregiver, and not somebody who really was at great risk. And the more time that went on, the less risk they perceived that I was at, to the point where my family doctor finally just said, "You know, we talked to the clinic, we talked to the clinic in Montreal, you're probably immune. You don't even really need to get tested anymore." I actually was in his office that day because I'd developed big lumps in my armpits, and all along my collarbone. And so, I was a 31-year-old woman there for—"Oh, lumps in the armpit, that must be breast cancer," and I was like, "Okay, you know, but there's this AIDS thing..." and he would say,

“No, no, you don’t need to get tested, we can send you off to an oncologist.” I said, “Let’s just do one more, and that will be my last one.” And about a week later I bumped into his receptionist on the sidewalk on my lunch break, and she said, “Oh, we cancelled the appointment with the oncologist. We’ve been trying to get ahold of you. Your doctor wants to see you. Can you come in tomorrow at 1?” ... And he said, “We don’t know much about women and AIDS except they die within about six months of diagnosis. And your HIV test has come back positive.” ...Oh my god, I haven’t told that story for a long time. [crying] I did not expect that.

GK: Do you want to pause?

JC: No, it’s okay. So, that was 1989, so my son was nine. And we had all those years, had been told that Randy was HIV positive, but clearly, he was not going to develop AIDS. And they told me my AIDS test was positive. I left that appointment thinking, “I’m probably going to be dead by Christmas. Randy hasn’t even adopted Gus yet.” I mean, it was just horrible. I just absolutely had this certain knowledge that Randy was going to survive and outlive me, because he was a carrier, and I had AIDS, and I was going to die of AIDS in about six months.

AS: So, the actual, the cruelty of the bad science, right?

JC: Yeah. It was not cruelty on my doctor’s part, he was—I mean I’ll never forget the look on his face. That kind of broke my heart, just seeing the look on his face. But, yeah. Around about that time I was being asked to participate in a study that the Partners of Hemophiliacs were... it was going on out of Montreal, and they wanted to collect Canadian data on transmission within the heterosexual community. So, they considered that we were captive cohorts. So, we were actually given misinformation on how to protect ourselves. In that same doctor’s appointment, my doctor was just horrified. He said, “I would call the clinic here every couple of months just to make sure I had the most up to date information. And they would call the clinic in Montreal, and they were the experts.” And, “This is the information that was being handed down, like, ‘You’re probably immune,’ ‘Don’t worry if condoms break,’ ‘You probably don’t even need to use condoms.’” As we found out, as time went on, there were other women within the hemophilia community who actually were *counseled* not to. One woman testified at the Krever Commission [The Royal Commission of Inquiry on the Blood System in Canada] that she and her husband, they were separated, and she was taken to one place and told she was a really bad wife, and the same thing was said to him, like, “She’s just not being supportive of you.” And you know, I just have to question, is that what they were doing? Were they trying to find out how long it would take without condoms? You know, the data existed in the States already. They’d already done—and I don’t even know if they did that kind of active study, or if it was a look-back kind of study. For me, the worst of it always was that girls as young as 14 were allowed to enroll in that study. You know, ultimately about 30% of us were infected, and many of those women had children, so probably about 30% of the kids born into those couples were positive.

GK: Just to step back for a moment in terms of some of what you are saying. You were saying that Randy was basically told that he would never develop AIDS, that he was just a carrier.

JC: Yes. That's the word they used. And that's the same way they described Hepatitis. He had A, he had B, he had non-A, non-B, which we now know is Hepatitis C. Yes, and they were told the same thing about that, that they were just carriers and that nothing would ever happen to them—that they'd *never* go on to develop the disease. Really, as we know, HIV is such a *slow* progressing disease, that they just weren't seeing any of them dying from it yet. Or if they were, it wasn't whole communities of hemophiliacs like there were whole communities or neighborhoods within the gay community, or the Haitian community, in particular in those years. So, it might be like one guy in northern British Columbia, another guy in New Brunswick, you know, who died of pneumonia, or something like that. I think hemophiliacs were often viewed as feeble and sickly. So, for them to die of some feeble sickly kind of illness wouldn't really have raised a red flag in terms of what might or might not be in their blood.

AS: Do you think also... in the US there was some talk about the way that people living in poverty wouldn't be able to access medical care, and that that would be a co-factor. Do you think that that people who were identified as hemophiliac would have had more medical care *also* might have changed the way that the disease expressed itself in those days?

JC: Well you know, I think they just really weren't looking for the existence of the disease. I think they all believed this non-scientific scientific fact that they were telling us, that it's just not progressing. I mean, I actually was told when I tested positive at my first appointment in the HIV clinic, "Well yes, that stuff about douching and the breaking condoms, now we know that's not true. What we actually believed is that the virus changed somehow in the anus of a gay man, and that's why women weren't getting infected or developing the disease." I looked at the doctor at the time and said, "Nobody's ever even asked us if we have anal intercourse. Like, you're just making a presumption of what we do or don't." And going back to the whole thing with hemophiliacs continuing to be boys, like I don't know if they thought we just necked in bed and went to sleep or something [laughter]. There were like, lots of hemophiliacs who, their couples had children, so it was going a little beyond what you think about "boy," or "boy-girl" kind of activities. It was just a very, very strange thing.

GK: So, in that early period, there obviously weren't many treatments available. But was there anything talked about at all with Randy or you?

JC: I think Randy wouldn't go on any treatment initially. Really, all there was then, I think, was AZT [zidovudine]. And somewhere in those three years, I think maybe 3TC [lamivudine] came along. So, there probably were about two options. Shortly after I tested positive, I was on the phone, I think with his hemophilia nurse, or doctor. She told me what his T cell count was, and I said, "Oh my god!" It was like 180 or something like that. I'm like, "Oh my god! Why wasn't he ever told this? Something's wrong here!" And this was the point where I just said, "Fuck it. We are not going to the hemophilia clinic anymore. Randy, you're going to the HIV clinic." What I was told is they felt that Randy wasn't listening to them, and wasn't hearing what he was saying about treatment. So, the team made a decision that they would wait until his T cell count was low enough and use that as a shock factor to force him to start treatment. Rather than saying, "Why don't you bring Janet in?" and "Let's have a conversation about treatment options." So, maybe that was the moment the activist was born. Because I just shrieked at his doctor, and said, "You all act like we're the ones

with the problem about this being a terminal disease and he's gonna die, but it's actually *your* problem. *You* can't deal with the fact that all your patients are dying. And you need to grow the *fuck up* and treat them like adults. We're out of here."

I called the HIV clinic the next day, and that was it. We went to the HIV clinic and he started treatment there. And like I said, I don't remember if I was positive then. I don't think I was positive. It might have been a few more months until we found out I was positive. At that point, I just stepped in. I went to every appointment with him from then on. That was the other thing; within the clinic they just made those choices. I think the big difference with the HIV clinic is right from the very start, in my opinion, the Nova Scotia clinic *was* pretty forward thinking in terms of, gay men were couples and, you know, that was their families, and they came to clinic together if they wanted to. I never had a problem doing that, I don't recall ever hearing anyone say, "Oh, that clinic wouldn't let my partner come in," or anything like that. So that was my recollection, that the HIV clinic was pretty forward thinking already in terms of what chosen families looked like.

GK: Right. Was there any discussion in those contexts that you can remember, about treatments for opportunistic infections?

JC: No, I don't remember even the progression of the disease ever really being discussed in that clinic setting. I think in the first three years he might have had two appointments at the HIV clinic. You know, they may have tried to talk to him about it, about treatment and such, but he was in denial. He didn't want to start treatment. But the one thing with Randy – and with pretty much everyone else in the world – if you can give them the actual information they need to make a decision, they pretty much will always make a decision that is in their best interest. So, you know, he wasn't being given the information he needed. They were telling him what to do, and he wasn't agreeing with them. They weren't telling him why, or "Here's the research." So, around that time I started doing a lot of research. Like, bookcases full of books on the immune system. I was still working in the microbiology lab, so part of my job was putting away medical journals. So, I was reading *The Lancet*, *The New England Journal of Medicine*, I was reading all the journals that were coming into the microbiology lab. So, I was learning a lot. I was learning a lot about upcoming treatments, and other places to access information as well. When I went to the AIDS Coalition, I think in terms of the disease and treatments that were available at the time, I was pretty well-informed.

Especially within the hemophilia community, there were very different side effects. I discovered, quite by accident, that one of the early treatments could cause esophageal bleeds. Randy was on that drug, I was like, "Oh my god, he's going to have an esophageal bleed." And sure enough, he had one. Prior to that, just nobody – the hemophilia clinic wasn't making the connection with the HIV meds, and the HIV clinic wasn't necessarily making that connection with hemophilia as a disease. All though they certainly knew about it, just that connection wasn't there. So, I was already – even before I went to the Coalition – having other hemophiliacs from across the country calling me and saying, "Well, they're suggesting I go on this," and "What do you think about that?" Again, I guess it was a kind of activism that I was doing. To me it just felt like, "Well, I kind of have the time and I can read this stuff, so that's what I can do here."

AS: It's actually so rare to have a microbiology background, right? So amazing.

JC: Well, and you know, I don't have a microbiology background! I was hired there as a secretary, and it just, you know, as budgets were cut it was like, "Okay, you have to do this job now." I mean, eventually I ended up working in a lab. But yes, budget cuts are what caused me to have the knowledge that I do! [laughter]

AS: And of course, later, it becomes also the way that the disease is being treated when it's based on a gay man model. That there are these drugs that predict cervical cancer, and that's not included...

JC: Exactly, exactly. Just, really starting to see the difference in the way women and men were treated. Even after I was positive and was becoming more involved, there still was a big part that I was just seen as a vector. So, either I could infect a man, or I could infect a child. I think, really, it was only women that ever were viewed as vectors. I mean, I would sit in lectures that were like, titled that, "Women as Vectors of HIV." It's like, oh my god, really? So, we're just a like a vagina! That's all we need to do now! [laughter] So I was at – I don't even know how I got invited to it – I guess it was sort of a community meeting, and there was a psychiatrist who was doing a lot of counseling, and I think maybe the clinic doctors were there. Actually, Randy was in the hospital at the time. It was probably about six months after I was diagnosed. I came from the hospital to the meeting, which was in another part of the hospital on a Saturday. They had this big list of communities, and women weren't on the list. It was like, "Okay, so why did you doctors invite me to this meeting?" I got very emotional, I mean I was just sobbing as I was talking. I said, "Why aren't women on this list?" and I said, "What really frightens me is that we are so ignored. What if the cure is within our bodies, and nobody thought to look there, because we're not included at all?" Afterward, some of the medical folks came over, "Oh, why did you get so upset? Why did that make you cry?" It's like, "Well, I guess that's what being invisible with a terminal disease will do that to you!" Especially with, you know, sitting in a room full of people who are supposed to be there to treat me, or guide me.

AS: Or maybe you're just an overemotional woman. [laughter]

JC: Well, yes. It was that time. Like, "There, there, dear."

AS: That's the implication. "Why would you be upset?" It's ridiculous.

JC: I know. I remember being so shocked at the question, like, "You're a psychiatrist! Why are you even asking me this? Like, I get that exploring feelings is part of your work, but..."

GK: So, there's a number of different strands of the conversation we could move to. Maybe the first one to go into in more detail is just how you and Randy got involved in the campaign for compensation, and how all that came about?

JC: So, we really bought into the whole, "It was an accident, we didn't know, 10% of blood comes from gay men," You know, Randy had *enormous* anger, initially, at the gay community. That was

really kind of encouraged. Not so much the anger, but the homophobia was really encouraged. So, we just weren't into that. "Oh, gee, it was an accident, we just didn't know." The Hemophilia Society was putting out a couple of documents that were starting to indicate that maybe it wasn't. The more I started exploring and reading about it, the more I began to realize that, in fact, while there was no test, they were fairly certain that whatever this GRID was, gay cancer, was also in the blood of hemophiliacs, we were becoming infected with it. And Don Francis, who was at that historic meeting, where we talked about how many people had to die before we do something about it, was quite involved in blood stuff as well.

In terms of making the decision to go to do the campaign for compensation, we were involved in the provincial chapter of the Hemophilia Society, thinking that was a support place for us. And it was, but it really wasn't. In part, I think, because we both have such big mouths, and we were asking the tough questions. So, I received a call from the nurse in the hemophilia clinic who said, "There's this reporter and they're looking for someone to talk to. I don't think it's a very good idea, but it's up to you, I said I'd pass it on. You can do it anonymously." So even at that point we weren't thinking that we were going to do anything. We met with this reporter, who was Dan O'Connell at CBC. We went in and said our names were Jack and Jill, and that we didn't want our faces on camera or anything like that. The more we talked to him, we just really started to trust him. So, he did, I guess about a thirty-minute documentary. It was going to air November 30th, the eve of World AIDS Day 1992, I think. Somehow through that process something kind of pinged for me. Maybe it's because I was now involved with the Coalition as well, and was sort of learning about what being an activist was. So, within that documentary, we talked about compensation and we talked about the need for an inquiry. And those are things I had heard from the hemophilia society, they were sort of their talking points, but I didn't really understand. They were like, "Oh, be sure and get this message out." So, I really sort of started thinking about it on my own and doing more research, and being involved in the provincial chapter, and they were sort of tippy toeing around and trying not to offend anybody. I think it's just kind of my nature that I could see they're not going anywhere; they're not getting anything accomplished. So, I said to the chapter president, "Well, you should phone the Minister of Health and set up an appointment." He said, "Oh yes right, like the Minister of Health is going to take time out to talk to us!" And I'm like, "Well, but he's an elected person. Like, we're his boss! He has to!" I was really kind of that uninformed, that I thought that was true. You could just call the Minister of Health or the Prime Minister. Well, it turned out it was George Moody, and he did agree to meet with us. I don't even know what I did, I made a move and I ended up President or Chair or whatever of the Provincial chapter, and Randy and I just kind of took it over and made it about compensation but also about the inquiry as well. And it truly was the right place and the right time. I remember the first time we ever saw George Moody was at that meeting at World AIDS Day.

AS: And can you talk about that meeting and what happened?

JC: Yes. So, I think both Randy and I were at the board of, I guess we were the AIDS Coalition of Nova Scotia at the time. So, we were invited to the meeting, maybe as board members. I was also associated with the Nova Scotia Women and AIDS Project, so I think I was there more as a representative of the Women and AIDS Project, but sort of two chapeaus. So, I didn't understand at the time, really, the importance of that meeting, or how historical it was. Because in my naivety I

thought that's how government worked, that they actually met with their constituents and listened to them, and they were doing things in our best interest. I really didn't appreciate the importance of it. I'm trying to think, I don't think we'd even met with George Moody at the time, within the hemophilia community. Do you remember?

GK: You're talking about World AIDS Day 1991?

JC: Oh, it was 1991. That's right. '92 was when we got compensation.

GK: '92 is when the meeting that I was at took place. But I think that you and Randy went – this is just the information I have – that you went public around the compensation stuff on World AIDS Day in 1991.

JC: Yes. And I think what I've always – and so much time has gone by – but the package was announced in 1992. So, I always think, "Oh yeah we did it in 1992." But it was World AIDS Day. So, the AIDS Coalition had a press conference to talk about World AIDS Day, and to talk about this meeting that we were having that night. It was the official launch of the Nova Scotia Women and AIDS Project. So, Jane Allen and I sat—and she really did the press conference. You know, I answered a question or two. And then I think the piece that Dan O'Connell did aired the previous evening, and then Randy and I had a press conference that morning as well, just to talk about the documentary and compensation and the blood supply. It happened quite quickly. In part, because there was a provincial election being called, and John Buchanan was Premier at the time. And the Conservatives were *really* on their way out, they were really bounced out, trounced in the election. So, George pretty quickly decided that the province would do compensation. He didn't want any of it made public. There were some meetings that were very badly reported in the press. Once the negotiations started, he had us agree that we would not talk about it at all, because he did not want it to be a campaign issue. It was separate from politics, in his opinion. So, the whole thing was done and negotiated before the election. There even came a point where I kind of hit a bump in the road, and I felt like the staff, I guess it was technically still his staff, it seemed to me they were trying to hold the process up until after the election. So, I – it's pretty stunning to think about it today – but I phoned him at home. He gave everybody his home phone number. So, I phoned him in the evening and I said, "Okay, this isn't going the way you said you wanted it to," and you know, that's what was going on. I got a call from the staff the next day to come in. And within just a couple of weeks, it was done. That was the other thing he said, "We don't want any announcement until after the election." I actually spent the night of the election with the Moodys, watching the election results come in.

And then the Liberal government changed it a little bit; they tried to change it a bit. My understanding was the comment from the Minister of Health was, had he been Minister of Health at the time, it would never have happened; compensation would never have happened.

AS: But since it was there...

JC: Well it was so public. I think, for them to have reneged on it... you know, the thing with the blood and with compensation, it allowed people who were homophobic but didn't even know they

were homophobic, it allowed them to care about HIV and to care about AIDS. Us being public, it allowed us a platform to talk about homosexuality and gay rights and drug use, and all those kinds of things. I know within the gay community there were quite a few people who were upset that we would talk about homophobia. I would say, “We’re dying because of homophobia.” We really are targets of homophobia in a way that, if you stop and think about it—the Red Cross refused to go meet with the gay community. The gay community was *begging* them, “Please, please meet with us, let’s be partners!” Plain and simple, it was homophobia. They were so afraid that their blood donors would find out, that they would *hear* the word gay or homosexual, and run for the hills and not donate anymore. So they just didn’t want anything to do with it. That’s part of the reason that they never properly addressed HIV within recipients. Not just hemophiliacs, but with people receiving blood transfusions as well.

AS: So finishing off that moment when the election had happened, the compensation deal was reached, and there was a slight change, they made some changes, but overall it was a win.

JC: It was. I always thought it was kind of funny and petty, but... so, there was this whole process. We had to fill out forms, you know, government. We agreed that we would have a press conference with the new Liberal Minister of Health, Ron Stewart, and George Moody did not attend, although he was invited. Apparently the new government invited him. You know, I think he’s a very decent man who thought, “Nope! New Minister of Health! Even though I participated in this, it’s their moment now.” So he did not come to the press conference. And what I found very interesting was, at that press conference, they presented Randy with his first cheque. And I don’t think I was very well liked in the government. They compensated everybody else in the province except me. [laughter] It took over six months for my compensation cheque to reach me. And I think that was just a little, “Pfft. Uppity woman, how dare you?” I really always felt that. And I would chuckle about it from time to time. It’s like, “So, you can cut his cheque, but...”

AS: I’m standing right here...

JC: The Minister of Health is right between the two of us at that table, “Here’s your cheque, Randy! But no cheque for you!” [laughter]

GK: Do you remember Mary Ganong at all?

JC: I do. Mary!

GK: She died about two years ago. We do have an interview on the site with her that Charlene Vacon did for the Valley AIDS Concern Group.

JC: Man, she was feisty.

GK: I think Mary at least told me she was one of the first people to get a cheque.

JC: Yes. And you know, I don’t know.

GK: She had big questions about whether to accept it or not. I do remember that.

JC: Yes. I think a lot of people did, because we called it what it was. We said, “This is blood money. This is shut up and die money.” You know, I think they really figured, okay, there had been this federal programme, and now there’s this provincial programme... I don’t think it was so much in our province that they thought we would shut up and die, but I certainly think once the other provinces and territories and feds came together, I think that was kind of how they viewed it. I mean, we publicly called it shut up and die money. Especially the initial federal programme that lasted four years. They just said, “Oh well, they’ll all be dead in four years. End of story.”

AS: Mary had been involved with the organizing, too?

JC: Well, you know, once it came down to the negotiating, I don’t remember if Mary was at any of those meetings. I think...

GK: The compensation was for her husband, right?

JC: Yes. And I think her husband was probably dying at that time, so I think she had other interests. But there were a couple of people from the hemophilia society that came to some of the meetings. You know, they presented some variation of what we ended up with. You know, I was working, I was in contact with Donna Ring, sort of in the background, because I really didn’t know anything about settlements, so she explained what a settlement was and what it might look like, and the kinds of things to take into consideration. So you know, I got really great advice from her.

AS: And can you say who Dawna Ring was?

JC: Dawna Ring was a lawyer at the time in the firm Buchan, Derrick, and Ring, an all-women or feminist law firm. And initially, when Randy and I were realizing that this wasn’t an accident, we thought, “Well, we probably should sue somebody.” So, we went off to see Dawna, and she was a litigator for the firm. She just really explained to us what was involved in that process and what it would cost, and that at the end of the day it might not be the best option, and you know, go ahead and go home and think about it and talk about it. Like, you know, do you really want to spend the last years of Randy’s life embroiled in this kind of fight? That really was the final decision, that when we really talked about it, we realized if we sued, probably a fairly good chance that Randy would be awarded something, but it would only be Randy. There probably would be a confidentiality clause. We just didn’t think that was fair. We thought, “We’re really vocal within the hemophilia community.” Randy never hid the fact that he was a hemophiliac. There were many hemophiliacs that were not ever really public, even about their diagnosis of hemophilia. There always was an association, which, I think, to some degree exists today, that hemophilia is caused by incest. And that, if you go back and read anything about Czar Nicholas, at that time, their son was a hemophiliac, they were second or third cousins. So that assumption was always made, that it was through the incest, through their being family related. But you know, his mother was a carrier; it’s a genetic disease. But so, I think a lot of hemophiliacs, while they knew that it was a genetic disease, and they understood what the progression was, they still—I mean, my son was at

school that's what one of their teachers taught; that hemophilia is caused by incest. It's like, "Wait a minute! No, it's not!" And he was asked to leave the class.

AS: Awful.

JC: Yes. So, a lot of hemophiliacs were very quiet. And I think also, they were forced to live a quiet life. They couldn't play baseball, they couldn't go run around in the park. Randy failed Grade 1 and spent seven months in the hospital because he got hit in the face with a baseball in Grade 1 and bit his tongue. It took them almost four months to get the bleed to stop. I think to some degree, I sort of was really a shock to that community; that I'm a big mouth, and I say what I think and what I feel. So, I think a lot of people were nervous about me or about us, and maybe didn't really want us to go public. And I know people that for years struggled with making the decision of accepting compensation, in part because they were so frightened that the information would get out that a) they were hemophiliacs and b) that they were HIV positive.

GK: I think from Mary, just from my recollection, there were two things I think that she was thinking about. One was, my understanding was that you were basically signing away any other possible action you could do against the government. But if my memory's right, her husband was infected at the time when in other jurisdictions, they were starting to actually do stuff with blood supplies, but they hadn't yet done it Canada. So, there was like this feeling that she had, that maybe this was a little bit different, and more severe.

JC: You're right. Now that you say that, there were other sort of complicating factors with Mary. So, her husband was not a hemophiliac. He received a blood transfusion, or transfusions, so there were different things that were going on, where Randy was receiving a product that came from anywhere from 4,000 to 20,000 donors, in a vat that they stirred around and then gave to him to inject.

So, Mary—I mean, I really am sorry that I didn't know her better. I think there came a time when there was stuff between the PWA Coalition and the Valley AIDS Concern Project. So then, I'm not sure that, for a while we were continuing to come together for board meetings. Maybe it was around the merger stuff with AIDS Nova Scotia.

GK: That would be a bit later, though, then this. Because it starts in '93 but it ends in '95.

JC: Right. So yes, it seemed for a while that every time I was at a meeting or a conference, Mary was there. And then it seemed that she wasn't. I respected her, and I liked her, I was kind of afraid of her. I'm not sure that we were friends that would grab a coffee together or yak on the phone. I don't think that was really Mary's style, for starters. And I think she was quite a bit older than me. I think she probably was maybe closer in age to my parents. Because I remember, even at the time, thinking that she was an old lady when I met her. But yes, she was really something.

GK: So just around the compensation issue, did it cause any sort of tensions – like, you would have been connected with the PWA Coalition at that time – between people who

were infected on different bases? That some people were getting compensation and other people would have perceived that they weren't?

JC: Yes. It really did cause a rift. First and foremost, we within the blood community were often referred to as innocent victims, which infuriated me. I hated that term. Of course, that's just rubbing salt in the wounds of all the other communities within the HIV community. I really did fight against that. So, just the fact that we were called innocent victims. And then the fact that there was money awarded. I mean, I whole-heartedly agreed, and tried to get something going with gay men that would say to me, "Well you know, they didn't do anything. They knew about HIV and they didn't do any education programmes or prevention or anything in the early days. So why do you get compensation and we don't?" Well, the reason we did, for starters, is there were legal issues that were involved that caretakers of systems did not meet their responsibility. So there were legalities involved.

You know, I think there probably should have been a class action lawsuit filed against one or two federal governments. Mulroney's government, and whoever was in before Mulroney. I think definitely the gay community, however you would define that, probably should have brought a class action lawsuit. I was fully in agreement that there should have been compensation, because there was a whole lot of information, knowledge, certainty around the disease, and they did *nothing*. Because as we've all heard, whether it's a real quote or an urban myth, it took care of two social problems: they'd all die of disease, and it would get rid of the gays. I don't know how you prove something like that in court. I always certainly was in favour of that, but I think probably to this day there are still people within the larger AIDS community that are pretty resentful. I don't blame them. I think there were little, tiny ways that I could try to give back; I never, ever put in an expense account at the PWA Coalition. I never took a single condom from the PWA Coalition. When I went to schools I was handing out 700 or 1,000 condoms, and I bought those out of my own money. I mean, regular donations and, you know, that was all the best I could do to try to deal with that. Then there was, we were so accepted publicly. That clearly was because of homophobia. I mean, this thing that happened to us, yes, but it also happened at least – I'd say eight or more years of the AIDS epidemic – the same thing happened to the gay community. So I think people could, like I said earlier, deal with their homophobia around Randy and I, and continue to ignore the AIDS community.

And then I think there was misogyny, which I'd never even heard of the word. I had no idea. I remember asking someone to explain it to me, and someone said, "Don't you think some of the people at the Coalition are kind of misogynistic?" And I'm like, "Uhhhh" [laughter] "Like, is that a rash? Can I get that? I don't know!" And I mean, it seems so silly now, but I *completely* disagreed with the person who said it. "Oh no, I'd never describe anybody here like that! They were all so welcoming!" But certainly, after Randy died, and after Randy's funeral, there was a *fury* unleashed, directed at me, that was really horrific to try to live through. I still never answer my phone because of that time. I've got an answering machine that can screen calls -- I've never answered my phone since '94—late '94 or '95. You know, there were almost one thousand people at Randy's funeral. There was national coverage of his funeral. That was a massive slap in the face to all those gay men that died before, because half—or, I can't say half the time, but many times not even their families would attend. You know? Small town Nova Scotia, would they even have a funeral, or

would they just stop talking about their son? So on one hand, I certainly understand where that fury and anger came from. But you know, I had an eleven-year-old son living in the house, where I picked up the phone and someone said, “You fucking cunt, you should have died with him,” click. So it was pretty bad.

I think what happened, in some way, Randy’s death was like a boil was lanced. A week after his funeral, there was a conference in Moncton. It was a regional – do you remember what those were called? Atlantic Region AIDS Conference, or whatever. And Lana Sherwood. Lana worked for, I think, AIDS Saint John, and was not positive, but she was absolutely beloved by the whole AIDS community, and she was an amazing woman. She was coming to the meeting on her motorcycle, and she pulled off a ramp into traffic and was run over by a semi, and died on her way to the meeting. People were just devastated. Because in our world, people died of AIDS. Nobody died like that [snaps]. Like, they were in the hospital, and you had time. And you know, Lana was part of us. She was vibrant and young and she had a foul mouth and she smoked and she drank with us. So, it was just *stunning* that she died.

Randy’s funeral had been a week before. Many people that were at the conference had been at his funeral. And that was really percolating away, certainly in Nova Scotia. And Wilson Hodder brought his partner Terry... Martin. Terry Martin. And you know, I’m not even clear if Terry was brought by ambulance, but he was on intravenous fluids, and we were all taking turns going in and caring for him. He probably died maybe a month later. So, there was all that to deal with, because man, Terry was like the Tinkerbell of the AIDS community. Like, anything good that existed in the AIDS community was in Terry. It shone out of him, like, no matter what he ever said to you, just sitting there, you’d just be able to breathe out and feel okay for a few minutes. It was just—there was so much going on that weekend. I arrived at the conference late. It was just a really bizarre weekend. Then there was just this massive event that took place in the hotel bar, where there was a mock wedding and myself and a man from New Brunswick were mothers of the brides, and... everybody was so drunk, I don’t know if I’ve ever been that drunk in my life. My hotel room was full of alcohol; I don’t even know where it came from! There were cases and cases of beer, and bottles of alcohol. This event went on, and I think it was just the frantic energy that we were still alive, like everybody was dying around us, but we were still alive, and like, we better make the most of it. It was almost lunacy, but it was really cathartic in a lot of ways.

GK: Just to clarify something. When you’re saying the AIDS Coalition, you’re referring to the PWA Coalition? I just want to try to be clear. Because this is before the merger.

JC: You know, I think...

GK: Randy died in ‘94—

JC: ‘94. So I think it was before the merger. The merger happened not much longer after that. You know, Randy and I certainly had been involved in that whole merger process, and we actually derailed it at one point. At that conference people were saying to me, “What were you doing at Randy’s funeral? Why would you have all those religious songs?” “Well, his parents were religious, so that was for them.” And you know, if you really stop to think about the religious songs, it was

“This Little Light of Mine,” “Jesus Loves Me,” it was all children’s hymns that were sung at his funeral. I did that on purpose, because I’ve always, always said that every person who has HIV is somebody’s child. How can you hate somebody’s child? I don’t care if they’re 97, they’re somebody’s child. So, get the fuck over yourself and stop hating children. And you know, even his funeral had to become kind of an event, and political. You know, it was an easy choice for me, because I grew up in the church and I was a kid in the church, and that’s what I grew up singing as a little child. So, for me, that was really comforting, and a lot of people got that, “Wow, I really got what you were saying with those hymns.” But certainly, many people, especially within the gay community, have been turned away by their churches and by faith groups. So, I understand where, “Jesus Loves Me...” Well, I’m sure a lot of people were sitting there thinking, “Well, I’m pretty sure he doesn’t love me! Because that’s what I get told on a daily basis.”

AS: And then there are lots of people who, some of the people we’ve interviewed have spoken about really finding a lot of faith, and having to negotiate that. I mean, you said it felt like having a... well, just to back up, from outside one of the things that feels really beautiful and political was precisely you and Randy not staying in a world that’s just saying, “We’re hemophiliacs, we’re innocent victims,” but instead *going* to the PWA Coalition and saying, “We’re working in coalition, we’re all affected, we’re positive.” And so you said it was like lancing a boil, and terrible phone calls and things happened after his death. Do you think there was something about Randy dying? Or something about him being alive that stopped that?

JC: You know, I think part of the progression that people saw in Randy, it was really noticeable, I think. This was a man who was mad and then within a very short time, I remember seeing at a CAS Conference, a Canadian AIDS Society Conference, and men who we knew were gay, he was in a wheelchair coming to greet him, and not shaking his hand but kissing him on the lips. Like it was an absolutely fine, normal thing. I think people saw that growth in him. You know, the first time we went to a board meeting at the PWA Coalition, I remember him asking—somehow it ended up being Randy and I, and Wilson and Terry, and I don’t know, it’s like we were a yin and yang couple or something. And I remember Randy struggling to figure this out, talking to Wilson and Terry, and saying, “So, Terry, you’re like the wife, right?” And Terry would say, “No, I’m not. I’m a man.” “Yeah, but you’re like, the wife, right?” “No.” And like—given Wilson’s temper—I mean, they really understood that he was really struggling, you know? He wasn’t saying, “Oh, you’re a nelly, so you must be the wife!” He wasn’t being insulting, he was trying to understand homosexuality and gay couples, and trying to normalize homosexuality. Like, okay, “How do I relate?” I mean, I kind of wanted to say to him, “Well actually, you know, I’m probably more like Wilson, so I guess that would make you the wife in our relationship!” [laughter]

I think Terry Martin and Randy, I don’t know, they were like these beacons, weren’t they? People really believed as long as they stayed alive we were all gonna be okay. And then for Randy to have died, and then Terry to be so ill, I don’t know. Within our community it was like the end of times with those two. And then for Lana, who was supposed to take care of all of us, because she didn’t have HIV, so she was supposed to be there *way* beyond the rest of us. I don’t know. It’s an insanity that I don’t even know how to explain.

GK: So, in terms of where to go with the conversation, in some ways we've ended up moving later on in the history of the PWA Coalition, I'm wondering if it's still possible to perhaps go a little bit earlier in the PWA Coalition. So, you get involved in it, and you're also involved with the Women and AIDS Outreach Project. So maybe you could just tell us a little bit about that? You've talked already about working with Jane Allen a bit.

JC: Yes. So, Jane and I became very close. I think by then, I was in the Coalition—well, after Randy died I was in the Coalition. Like, I had an office there. I was a volunteer. But in terms of the Women and AIDS Project, there just were not many women willing or able to be as public. I mean, I'd already taken a lead. Just to back up one little bit, part of the reason Randy and I were able to make the decision to go public was we knew we could pack our bags and go in the night if people showed up throwing Molotov cocktails in our windows, as happened to hemophiliac families in the States. So, we could just go. And we could do something as simple as move to Halifax—just move back to Halifax and pick up our lives that we lived in Halifax before we moved to Dartmouth. And so of course, then being able to be public with the Women and AIDS Project, I already was public, and you know, nothing awful happened to me, at least not overtly.

So, it took me quite a while to even understand what the Women and AIDS Project was. I didn't really understand, you know, because I'm white, upper-middle class, heterosexual, I don't understand why we have to divide ourselves by communities. Because really, other than the woman part of me, I never have to do that. I can just prance through life, getting apples and peaches off whatever golden trees are around me, because of my position in the world. So, I didn't really understand any of that. And I gotta hand it to Jane, it took her a long time to get that through my thick skull. Because of that, that's how I was able to come to an understanding of other communities. I really learned about needs assessment and community building, and that's what the Women and AIDS Project was about. Really, our goal was to put the Project out of business. So, I guess it was one part of the work, we traveled to many, many, many towns in the province, meeting with women's groups and AIDS service organizations and church groups and PTAs, because what we were trying to do was normalize HIV, and see it through the lens of feminism and women and that we are at risk, and that HIV was actually, in a lot of ways, HIV infection was actually a symptom of the greater ills within the community of women. So, whether it was not enough money, or being in violent relationships, or judgments for having children out of wedlock, all the things that affect women – race and education, and all those things. So, I think we were fairly effective. I don't know how we ever went back and measured it, I'm sure those were done. But you know, I just remembered it seemed like we met with thousands and thousands and thousands of women, and I just became more and more educated.

There was the part of the project about helping positive women to learn to empower themselves. I remember one of the women in the project did this amazing video that probably still exists somewhere about... I think she did a lot of filming and interviews during a women's retreat, about how women empowered themselves, and who they saw themselves as... so to be involved from that perspective, in a way it gave me a place to go and be a positive woman, because that didn't really exist within the hemophilia community, and without the Project it didn't really exist at the AIDS Coalition, either.

I remember really struggling after Randy died. Quite some time after, I was really struggling with treatment, and I remember talking to one of the positive women who was a few years older than me, about treatment and that I was thinking of going off, that it was just getting too difficult, and by that point I think it had probably been about ten years, and it was just infringing on my quality of life too much. So actually, we had this conversation, and there were probably four or five other positive women around, and the woman that I kind of was directly talking to didn't say too much about it. After, when we were alone, she really took me to task. Like, "Don't you understand your role in this community? You're a leader. *You* don't have the option to make that decision and to make that choice." You know, I was told that about a couple of drug studies as well, like, "You're a leader, you need to be on this drug or in this study." So, while there were times it was a place for me, a lot of times it wasn't. I still had to *be* something. There was one woman in Newfoundland who was in a similar situation to me. She and I really bonded and became close.

AS: Because that's so important, right? It's actually such a burden to have to be the person who was always moving ahead and being strong...

JC: Yes. I think in some ways that then forces you to. I can't say that it caused me to not deal with my feelings; I found a way to do that. But I think in some ways I may have ended up becoming closer to the staff at the PWA Coalition than I might have been with other members there. Wilson Hodder and I—man, we had a bizarre relationship. You know, to some degree he'd tell me about being an activist as well, and he *really*, deeply cared for Randy. But we had our moments. I learned a lot from Wilson.

Oh, we were talking about the Women and AIDS Project as well, so the empowerment of women. For Wilson, it was an odd support that the AIDS activist in him supported it but I'm not sure Wilson, the man, really 100% understood it. At the same time, with the Women and AIDS Project, it might have been maybe a year later, the Black Outreach Project started. They were at that meeting at well. The Women and AIDS Project had just announced that morning at the press conference their existence. So, we did some partnership work with them, but, you know, they were doing a damn fine job within their own community. I think maybe we probably got a little more from them. And there were a ton of projects. So, the Men who have Sex with Men Project came after. I mean, the Women's Project still existed, but Men who have Sex with Men came after that. Again, it's interesting. So, a man would call the hotline and say, "Well, I'm married to a woman and I have kids, but I touched someone's penis in the bathroom on the weekend, am I gonna get AIDS?" "Janet!" And I'd have to take the call and say [laughter] "Okay, I know I'm a manly woman, but I'm not a man! I shouldn't really be doing this counseling!" I think really what it was, was these men calling were so frightened. Presumably they were gay or bisexual, or questioning, and for some reason they would just feel more comfortable speaking to a woman. I guess that felt it made them less gay if they were talking to a straight woman or something. I actually ended up, strangely, being friends with two of those men's wives. One of the men was positive, and he was very, very open, because he asked me to come home with him to meet his wife and children. So in that way, all the projects just had those moments, that I experienced, and I'm sure lots of other people experienced lots of other moments.

So, the Women and AIDS Project, we were also able, because I was involved at a national level as

well, we were able to then start pushing for women-specific research, women-specific treatment, and for women to be included in clinical trials, and to have clinical trials be representative of the actual community. You can't have all white gay guys and three women, and no one from the aboriginal community, or the African Nova Scotian—you know, these trials have to be representative. Then the other thing we were able to bring up is that most women, involved in the Project anyway, I mean the clinical trials, have children. So, like, should they be lugging their four kids, maybe two of their kids are positive, they're not going to lug them in, you know? The women are lucky enough if they're even getting to their own medical appointments, never mind an appointment for a clinical trial. So, we were able to start pushing for, not paying the women to participate, but at least to start covering some of their costs, like babysitting services. With the PWA Coalition as well, it was a little bit of a fight to get the board to agree to pay for childcare. You know, we started off talking about women, then we talked about parents, and then the way we were really able to push it over to the edge was to say, "Well, if you have to leave your dog in a kennel, of course, if that's your equivalent to a child, of course you should get your kennel fees covered." So many gay men had dogs and no kids, so it's like, "Okay! We'll pass this motion!" [laughter] Kids and dogs. Once they're around everything's okay.

AS: It's hard to write into a grant that we're going to be available to have people go home and meet the wives of people who call in... right? And yet that's such an important part of the work, is this kind of making a relationship and a connection.

JC: Well, and I'm not sure. I guess because it was mostly gay men that wrote the proposal, they don't really know what straight marriage, or someone who thinks they're straight and married to someone, it's a different kind of relationship. I mean, especially in a small province like Nova Scotia.

AS: Yes, how do you talk about sexuality and monogamy?

GK: So, I don't know how much time we have left, because I know you have to be somewhere at a certain point in time. But maybe really quickly, around the meetings with Moody around the provincial coalition. If there's anything you remember about that whole process? This meeting occurs in 1992, so you would have been involved for a while in the PWA Coalition.

JC: But wasn't there one prior to this?

GK: I'm sure there were, but I wasn't involved in them.

JC: My recollection is, like you said, Summer—August or September or something—we went to the PWA Coalition, and then that World AIDS Day we met with George—we, the whole committee, and then... because we did all the press conferences that day...

GK: So this one in 1992, I don't think there was a press conference that day. I think there was just a meeting with Moody. So I think you might be thinking about the 1991.

JC: Yes, I think I'm getting the two of them confused.

GK: But that was a very important day.

JC: Yes, and like you say, I don't think I really understood the historical significance of that meeting. And now that you bring this up, I'm not sure I even... is this the one where Tuma [Young] talked?

GK: So Tuma would have talked at the actual meeting. And for some reason you and I were selected to send this letter off...

JC: Well that explains it, because I've always had this feeling that I went to the meeting not really understanding the importance of it, but somehow I seemed to understand the importance—because there were two meetings. Okay. So, onto the second one. Yes. So, I would have been on the board for a year, over a year by then. And Randy was becoming quite ill at that time.

GK: Yes, I don't think Randy was at this meeting.

JC: I think you're right. And that was the other thing, it's like, but he was there! But no, he wasn't, he was not at the second meeting, and I suspect probably because he was ill. And that's why the hemophilia society is not on there. I was there with the Women's Project and I was a board member of the Coalition by then. Geez, you know, I really don't... you know what I think? This thing went on to kind of become the AIDS Strategy, didn't it?

GK: This was a meeting that was attempting... they produced a draft of the AIDS Strategy. Our meeting with Moody was really to critique that, and then the AIDS Strategy comes out—

JC: After the election.

GK: The AIDS Strategy comes out in 1993.

JC: Right.

GK: And it doesn't have much in it.

JC: No. They had just hacked away *everything*, including the budget. So they had this wonderful strategy with not a cent committed to any of the work.

GK: That's right.

JC: By that point we had a different government, and I think they talked a good game. I'm not sure that the commitment truly was there. I think we were promised a lot of things from that government that didn't materialize. You know, they were a Liberal government, so they were all "Austerity this, austerity that," much like the current Liberal government. But I don't think they ever even responded. I remember we went through the strategy, the whole group of us, and then

we had a press conference to comment on it, and we may have even done a report card kind of thing, and it got a failing grade, because we talked about what a full document it had been and the work and commitment that went into it—it was like 17 pages in it. What came out was very brief, and it kind of didn't say anything. I'm trying to think, did we continue meeting with Ron Stewart before the strategy came out? I think we did.

GK: I don't know. It's partly because I was only in Nova Scotia until '93.

JC: Yes, I think we did, because it seems to me the person who was Deputy Minister under George Moody was his Deputy Minister for a brief time, so she was at that meeting. So I remember we were seeing kind of the first printed version of the strategy, and they had completely taken away "Risk Activities," and changed it to "Risk Groups." I remember talking directly to the Minister and saying like, "This is ridiculous. Women aren't even on this list. By doing this you are negating anybody else thinking that they're at risk." You know? I said, "If you're going to do this list, then it has to be 'Women,' and it has to be 'Persons of Colour,' and it has to be 'the Elderly,'" and they're like, "Oh no, the elderly don't have to be on that list!" and I'm like, "Last week the state of Florida declared an epidemic in the elderly population in Florida." And at that time they were blaming it on men going and finding prostitutes, and then going home and infecting their wives. And the Minister's comment to me was, "Well, I would want to see proof of that. I'd want you to provide me with the data for that." I said, "Well, you're the Department of Health. I think you can get it." At that point I said, "You know, it's probably better if I just leave this meeting," and he said, "Oh no, please don't." But I think I did leave the meeting.

Then just a very short time after—I mean, I can't even call it watered down, it was so far beyond watered down. There was just nothing of substance; there was some preamble of the history that probably wasn't even that accurate, you know? All this work that was going to be done, that was already being done, and funded by and large from the federal government, so they just kind of jumped on that. I mean, eventually I think we got a fairly decent AIDS strategy, but it did take us quite some time. Then, really it just kind of all went to hell. I remember it was on the Ministerial Advisory Board or whatever the provincial one was called, and we were reviewing the seventeenth draft of the document, and I just said, "Okay, I quit. I just can't do this. I can't spend the rest of my life reviewing a document that's never gonna be..." "Well, we had it tabled in the legislature!" "But it's a *draft!*" So like, what does that even mean? So honestly, that was really the last time I was involved with any kind of provincial AIDS strategy. I don't even know if we have one. I presume we do, but I honestly couldn't say for sure. And the same federally, I mean I was certainly involved. Surprisingly, Brian Mulroney's Conservative government provided funding for the first national AIDS strategy.

AS: Why did that happen?

JC: I think because he'd been at a conference, and he was sort of being forced to talk about HIV. I think the conference was in Montreal.

GK: Oh, you're talking about the international one.

JC: Threw peanuts at him.

GK: The national AIDS strategy was actually in the works before that, because of the stuff that had happened in Toronto, at a cross-country AIDS conference that led to the burning of Jake Epp, who was then the Minister of Health, in effigy. So a number of different things come together.

JC: It's interesting. Now that you talk about Jake Epp, people within the hemophilia society became friends with him through negotiating the federal project. And god, I haven't talked about this for a long time. I remember somebody within the National Hemophilia Society saying, "Well remember now, Jake Epp is a friend to us." And it was right up there with "10% of blood comes from gay men." I could go and do what I was gonna do, so long as I remembered he was a friend to us. And I mean, in some ways, I don't even really know if I knew we had a federal minister of health. I was really, *really* uninformed in terms of government when I started all of this. Which explains the, "Well, just call the Minister of Health!"

GK: So, I'm going to suggest we try to deal with three more questions. The three questions that I've been thinking of talking a bit more about is: one, coming back to the merger of the PWA Coalition and AIDS Nova Scotia, the other one is the concerns you've raised over AIDS treatments and their impact on people's health, including your own. Because I don't think, anyone we have talked to so far has talked about this. And then, just maybe more general reflection on your part about how your involvement in, we won't use the word "activism," but let's say "AIDS organizing," how it actually impacted on your life in a more profound way. I think, because you've already mentioned a number of people who have died, or who you remember. And maybe when we turn the thing off we can talk a little bit about other people we might want to talk to. Does that sound alright?

JC: Sure. Sure.

GK: So, you already mentioned a little bit about the merger of the two groups, but maybe you want to come back to that? So, it starts in '93 and completes in '95.

JC: So, as I recall, the federal funders said, "We're only going to fund one organization. One kind of provincial organization in the province." So, I think at first, both organizations were like, "Well, it should be us!" I remember even at the PWA Coalition, that there was talk. We talked about a merger, we also just had conversations around, "Well, why don't we just write a proposal? Let's just send a funding proposal that we're it. Let's not get involved with them at all." There were, to be kind, I'll say intermittent bad feelings between the organizations. A lot of people thought AIDS Nova Scotia was more government-type organization, wasn't *really* for people with HIV, that we weren't really encouraged to be involved. I personally hardly ever went there, other than for maybe the odd meeting. I mean, I do think there's some truth in that. It's almost like, we were the activists and they were the administrative group. Maybe they were doing more stuff around provincial policy, although we certainly were doing that as well. But you know, we are a pretty small province. We had two organizations doing a lot of the same work. They were politer and we were more in your face. So then we started having joint board meetings. First of all, I think the two

chairs were meeting, and they started the process. I think Ross Haynes was the chair of AIDS Nova Scotia, and Wilson Hodder for the PWA Coalition. So, they were having conversations, and then it became the two executives, and then eventually it became the full boards would meet regularly. And I think most of the people at the PWA Coalition were not really in favour of merging. I think that's true of a lot of the staff, although they were sort of in a position where they couldn't say yea or nay. But we had a good thing going there, and it was working for the majority of us.

So, we had these board meetings. And there came a board meeting at the AIDS Coalition of Nova Scotia, where several of us on the PWA board talked about how we'd gotten burnt out with all this talk, and we were clearly seeing more and more differences between the two organizations, we weren't seeing that a merge was such a great idea. So, I think it was Chuck Gillis and I, put forward a motion and seconded it, that we have a six-month moratorium on any discussion about the merger, and just take a break and let us get back to the business. Because people at the PWA Coalition, some of the people living with HIV were starting to get scared, and feeling that they were going to lose their place, and maybe they'd had a bad experience there—there was all kinds of stuff going on. Still at that time, still lots of people were dying, and to merge, I think people were seeing that it would end up being a loss of our organization and our voice. People were tired and they were scared and they just kind of wanted to rest. The motion passed unanimously.

So then there was one more joint board meeting planned. Wilson had been instructed to pass that onto the executive, or the other chair, so we get to the board meeting, and the first thing on the agenda is, let's come up with a name. So, we're kind of listening to this and thinking, "Considering we just made a moratorium, this seems an odd discussion to have, but we'll go with it for a bit." And we listened for a little while, and then I put up my hand and said, "I'm not really sure why we're having this discussion, because at our last board meeting we passed a motion saying that we would have a six-month moratorium on any discussion." Well the *room erupted*. Oh my god, there was screaming and yelling. I don't even know who was chairing, if Ross and Wilson were chairing together. I don't think Wilson was very happy with me. But thank god Randy was there with me. Thank *god* Randy was there with me. And there was also staff from the Coalition there who were very supportive as well. So I don't know who it was that suggested we take a break. So somehow, through all this discussion, it then became, the two boards will vote on if we're going to be opposed to the moratorium vote, and we'll go ahead and come up with a name, and make a motion that we're going to go ahead with the merger. And lots of people in the room were really angry. So, Randy and I were out in the hall having a drink and I said, "It's probably best if we leave, because maybe the discussion will be a little calmer if we're not in the room." You know, I would say most of the Coalition people didn't want any of these votes to happen. So, Randy and I left and went home at the break. And we got a sort of cackling phone call from some of the people at the Coalition the other day saying, "Oh my god, we didn't even realize this, but when you and Randy left, you took quorum." [laughter]

GK: People were thinking it was a strategy on your part! [laughter]

JC: "Quorum? What's quorum?" [laughter]

AS: "When did we ever worry about that?" So they couldn't make the vote?

JC: No! They couldn't pass any of those motions! [laughter] Because by then, there were two separate boards, but we were also this quasi-single merged board.

AS: Right. But not even officially merged.

JC: Right.

AS: Wow, what a mess.

JC: Yes! So then... maybe Larry Baxter, I don't know, Larry and Ross were back-and-forth chairs of the organization, or whatever. Or maybe Larry was still chair, I don't know. Anyway, I ended up having to have a meeting with Larry and Wilson to sort of try to mediate our way out of this. I mean, eventually the merger happened, but I think there was enormous distrust now between the two groups. The night of the vote, I don't even remember now what the motion was, but it was a positive woman who read the motion, and I remember her legs under the table, going like this [shaking]. And it was something that was going to go against ACNS [AIDS Coalition of Nova Scotia]. I think we were sort of making a motion that we would be at the head of the table, and you know, they'd be below the salt, sort of. So, whatever the motion was, it was very contentious. We voted on it, and it passed. And I remember being physically chased down the hallway. I thought I was going to get punched that night. Like, somebody actually stepped between myself and the person that was that angry. [laughter]

AS: From...?

JC: From the other side. Yes.

GK: So how long did you stay connected with the new, merged group?

JC: Oh, I was there for quite a long time. Wilson came to talk to me and said, "I think my health isn't that great, and I don't think I'm going to run as chair again." I was vice-chair at that time. He said, "I don't think I'll run again, so I'd like you to work with me," for six weeks or six months, or whatever it was, "to learn how to be chair. And at our meeting, I'll put your name forward, and you'll be elected the next chair of the Coalition." So I worked with him, and sat in on meetings, I mean I was part of the executive anyway. But you know, I kind of sat at the side of his desk and listened to phone calls and all of that. And then along came the meeting, and somebody nominated Wilson as the next chair, and he accepted the nomination, and then he sat quiet and did not nominate me. So I said, "Well, I'm going to nominate myself. I nominate myself for chair of the board." And Lorne... oh god...

GK: Lorne Izzard?

JC: Lorne Izzard seconded it. And you know, because many people were aware that that's what was going to happen.

AS: That was the plan.

JC: So, he seconded it, and it was pretty—no, it wasn't a unanimous vote for Wilson, but it was pretty close. I stuck around for a couple more weeks after that. And, you know, confronted the people that were sort of involved in it. They were like, "Oh, oh, what do you mean? We didn't do anything!" I'm like, "Yeah, I think the die is cast."

AS: Did Wilson ever explain what happened?

JC: Yes, well you know, that kind of stuff happened. And it might have been a last minute thing, that Wilson decided, "No, no, I still do want to be chair." I don't want to believe otherwise, you know? I think Lorne resigned from the board the next day, or fairly soon after. I don't know that he ever was involved again. I stuck it out for a little while, but it was becoming increasingly clear that I wasn't really welcomed there anymore. I remember asking a question, I think we were organizing the AIDS auction or something, and making a statement that, "If the funds are raised from the auction are going to go to pay for our photocopy rental, then that's what we have to say." Like, "If they're not just going to the health fund, we have to tell the truth. Because there's lots of choices out there." I think that was kind of the final nail in my coffin. I think we were in the Lord Nelson hotel at the time. I don't think I even went back on Spring Garden Road for probably six months. I was so nervous and frightened, and I just didn't understand what was going on, and I kind of didn't understand who was doing this or why. I'd been on a national board, I'd been on CTAC, which was the Canadian Treatment Action Council, I was there as a Nova Scotia representative, and while I was at a meeting of CTAC they had some emergency board meeting and voted me off as a representative and didn't tell me. Yes. It was my time to go.

I stayed involved at a national level, probably for another couple of years. I went through periods of time where I would wake up in a hotel room and think, "I don't know where I am. I have to look at my agenda on the table," or I'd open my curtains and say, "Oh, it's flat, I'm in the prairies." There was one day, it was just ridiculous, that I flew to Quebec City to drop off luggage, then I think later that night I flew to Winnipeg, I did a keynote address at a conference in Winnipeg, then I flew from Winnipeg to Ottawa for a meeting the next morning. After I did the keynote address that evening, the next morning I flew to Ottawa. When that meeting was finished, I flew to Quebec City to attend two days of meetings. I just thought, "This is crazy! I've been in three provinces *today*."

And you know, the other thing is, there were more and more and more women involved. I think that was just a natural progression. There were more AIDS service organizations, and I think women were feeling safer. There was a national Women and AIDS Project by then. So it just kind of felt like I could step back. You know, ten days after Randy's funeral I was in a high school in Bridgewater. In part I was doing that because, I cried all the way to Bridgewater in my car, and I cried all the way home, because there was nowhere for me to grieve other than by doing that. That's really not very healthy grieving, driving a hundred kilometers down the road, sobbing your face off. It's not that I was completely alone, of course. I had my family, and people from the PWA Coalition, staff and other members of the Coalition, of course they were there. But I guess, sometimes grief is lonely. You know? You can only grieve in front of people or with people so much, and then you just have to do it on your own. And my son was getting older, and needing me

in a different kind of way. And then, probably in about '98 or '99 I sort of started packing it in, in terms of national work. I really wasn't doing much provincially then I don't think. I kind of started packing it in. And then in '99 I started new medication and I had a heart attack. And that was sort of like, "Okay, it seems like it's the right decision."

AS: Time to slow down.

JC: Yes.

GK: This would also be an interesting bridge to talk about treatments and their impact on you, but also more general concerns at the time.

JC: Yes. So, nobody will actually come right out and say that the treatments caused the heart attack. I was the first person in Nova Scotia with HIV to have the myocardial infarction. And less than a week later, a guy from New Glasgow had one. It was like, just boom, boom, boom [snaps], it was like every week somebody was having some kind of fairly major cardiac event. And then we were seeing it across the country as well.

AS: And the new meds were just—were they new for everyone?

JC: Well, there was a new class of drugs. I've been on several of them. Back then, you sort of, to some degree, we treatment hogged. If you'd gotten in a clinical trial, they were all blind [double anonymized placebo controlled trials] so you didn't know what you were on, but when the study would be unblinded and you'd find out maybe you were on the drug, "Oh, well I'm going to stay on this," and then "Well another drug's approved, this has different side effects, to hell with that I'm going to go on that," and so what that ended up causing was many of us became resistant to many drugs. There are a couple of classes of drugs that I'm completely resistant to. But in terms of treatment, oh my god, for a little while the joke in our clinic, between me and my doctor and a couple of the other staff was, "If there's a side effect we haven't heard of, when Janet comes in we'll hear about it." [laughter] So I started lactating about three weeks after I started treatment, and they couldn't find anything in the literature. And when they did blood work, my prolactin level was about 80 times higher than a nursing woman. So we stopped the drug for a month or so, went back on the drug, I started lactating again. So one of the interesting things about that is when I asked at clinic, I said, "So, we know there's enough HIV in breast milk to impact a baby, but do we know of the concentration, or the level? Is there enough HIV in breast milk to infect an adult?" And my doctor said, "Well why would you want to know that?" And I'm like, "Well, I'm dating someone and I'm in a relationship." "Yeah, okay..." Like these are part of it, you know! And nobody could ever give me an answer. So the solution was, "Well, just go off that drug."

AS: Yes. This is amazing, right? Like, these areas of just, "We're just going to be completely ignorant about that, know that we're ignorant, and not do any investigation to answer that question."

JC: Yes, because you know, again, it's I guess, talking about women's sexuality. And you know, I was getting up there in years. I was, I don't know, 41 or 42, so for sure that should be over.

AS: Yes, I'm 41 and I'm done! [laughter]

JC: I remember we used to talk about Crix tits. So, Crixivan was a drug that... oh, it was in the new class, protease inhibitors, so people were reporting buffalo hump, like big fat pads at the base of their neck, and fat shifting around on their bodies. And when I went on Crixivan, probably I lasted a month, I went from my whole life, from the time I was about thirteen, 34B breasts to 38C, you know? Things like I'd open the freezer door and wham into my breasts, because I just wasn't used to it! [laughter] They were gigantic. And when I went off Crixivan it went away. And the strangest thing was, I was still young enough that I was wearing cute little mini dresses, and I had a couple of dresses that were sort of smock style, and we were doing this big political event with... so, Alexa McDonough, Terry Donahoe, Mary Clancy, I think it was federal. I think they were all running federally. I came up with this idea that we were going to do a carwash as a fundraiser and sell it at the AIDS auction. Then the candidates would show up and wash your car. We got huge coverage, they all came in their busses, and it was great. But I wore this dress, and of course I was like, part of it, so I had to do some little opening welcome to all of them. And when I saw the media coverage, because my boobs were so big [laughter] it was like I was wearing one of those little dresses where the back just flips up, you know, that's the funnier side of side effects.

So, I was in many, many drug trials. In some ways, for all of us, I mean I talked earlier about having someone say to me that it's part of your responsibility. You know, I think all of us back then, in the '90s, really felt a responsibility that if we were going to die – which probably we were all pretty sure we were – that at least we could do something to ensure that people who come after us, maybe they might not die as quickly, or maybe we might be able to help come up with medications that would be easier to take. So I have to say, from all the activism I ever saw, almost all of it was hugely based on altruism, because none of us got rich on it. I would say drug trials, that just was pure and simple altruism, because we had *no* idea what those drugs were going to do to us, absolutely none. I was in a drug trial where I had to have a catheter inserted right into my heart, and then every day I had to spend about, I don't know, six or seven hours – so did everyone else that was in the trial – six or seven hours receiving an intravenous treatment, and it went directly, I guess, in and out of our heart, or however that works. So there were some huge, scary trials.

Oh god, I think the one that really stands out the most clear for me, was a drug called ddI [didanosine]. I cannot remember the other name of it anymore. It's literally decades. But first of all, it came in this sealed envelope, and it was a powder, and you had to mix it with water, but it wouldn't dissolve—it was so buffered, so it would kind of sit on top, and it was like trying to break up chalk and dissolve it. So you'd like, suck all this goo, and it'd be all over your teeth and burning your gums. And then it came out in pill form, and I measured: one pill was the same size around as a loonie, and it was as thick as two loonies piled on top of each other. And we were at first told we couldn't break the pill. They were completely buffered with a chalk substance, so you'd swallow it, you'd have like, two loonies there, and you'd drink your water and try to get it—so, I think some people probably ended up with sort of burns in their throat, and finally they said, “No, you need to at least break it up a little bit.” And very interesting, that trial, so of course we didn't know anything about side effects other than what would've been written in the informed consent. So I went through *every single side effect*. And I remember Wally Schleich saying, “We don't even need

to pretend anymore. It's so clear that you're on the drug. I shouldn't be saying that, but it's just so obvious. The signs of the neuropathy and everything," and when they unblinded the study, lo and behold, I was on placebo. My blood work improved. It was an absolute true placebo effect.

So, when protease inhibitors came out—there were the non-nucleoside, whatever, AZT, 3TC, d4T, ddI, that whole class of drugs. Then along came protease inhibitors. People call that the Lazarus class of drugs. Like, people literally were getting up off their deathbed. I'm friends with a woman who was passed on out of the HIV clinic, into the palliative care unit, and she had to fight to get the drug because it just was believed, "You're probably dying, why would we do this?" So that would have been... '94, '95. She's just returned to work. And struggled all these years to not go back to work, because her health was quite improved. I think a lot of us that go through that, we don't really trust it. I went on the drugs and there was a great improvement and all of a sudden I wasn't really having wasting syndrome anymore, my blood work was really improving, and *bam*, five weeks later I had a heart attack. So you really sort of had to weigh that out.

Even at that point... first of all, I had the heart attack. While I was having the heart attack I actually spoke to two doctors on the phone, just describing the symptoms. Well, one of the side effects of the new drug I had just started was severe heartburn. So, they were prescribing a heartburn medication for me. I mean, I was doing physical stuff in my house, taking everything off the shelving and washing and cleaning it, I was up and down the step ladder, my arms were going up and down for a couple of hours, and I'm thinking, "Okay, I've done too much and my arms are hurting." And it was both arms, and there was no heaviness in my chest. So, neither of these doctors thought heart attack. And I was a woman, and I was 42. So, I woke up, probably at about 2 o'clock in the morning, and I've just never been so nauseous in my life. I thought I was going to turn inside out. I was retching with such force. But I didn't throw anything up—just this massive retching. And then I was absolutely fine. Prior to that, I was trying to sleep with my arms up, because it hurt too much to even put my arms down. And then I went back to bed, and boom [snaps], I just fell into a deep, deep sleep, got up the next morning, felt a little tired, but I was kind of up till 2 in the morning, and I had a hair appointment. So, my doctor called me in the morning and said, "How are you feeling?" I said, "Oh, I'm great. Whatever it was seems to have passed, so I'm going to go get my hair cut." So, I don't know how he did this, but he tracked down what salon I was in, who was doing my hair, and said, "No, I thought you were going to be like half an hour. You need to come in right now and get blood work done." And I'm like, "Well, I can't! I've got foils!" [laughter] So, I continued getting my hair done, and then walked over and had blood work done. I'm thinking, "Well this is all kind of silly. Like I feel better, why are you doing blood work?" And he called at suppertime that night, and of course he knew that I didn't answer my phone. And I was having such a healthy dinner of Swiss Chalet chicken, and he's like, "Janet, if you're there, pick up the phone! Janet, if you're there, pick up the phone! It's David!" And I'm sort of ignoring him. And then he said my partner's name, "If you're there, pick up the phone! I need to talk to one of you!" So, I picked up the phone, and he's like, "Okay, you need to go to emergency right now." And I'm like, "But I'm having supper," and he goes, "No, you're not finishing supper. You need to go to emergency right now." And I'm like, "Well, can I pack?" "No! Go right now. And if you won't, pass the phone over and I'll tell him to get you there." Then he's like, I thought he said, "Oh your CK [creatin kinase] values are up!" And I'm like, "Whatever that means." So, off I go to the hospital. He's like, "There's a cardiologist waiting there to meet you." So off we go to emergency, and there's

a cardiologist there, and he's doing all these tests, and I keep saying, "But I feel fine! It was just heartburn. I'm fine now." And I said, "I did this great big thing where I was thought I would barf, but I didn't," and he goes [snaps] "Classic! Classic symptom!" But he didn't tell me of what. [laughter] So he goes through all this, and we're there for hours, and it turns out my sister was at emergency, so we're having like, this little party in my little curtain area. And then they say, "Okay, there's a bed in intensive care for you." I'm like, "What? Why?" So they take me up to intensive care and it's like in that bubble room where they can see in every bed. And so it's the nurse who's admitting me and, "Oh, here's an Ativan." I'm like, "I don't want an Ativan. What are you giving me an Ativan for?" She's like, "Well, because it's standard. You need an Ativan to calm everything down," I'm like, "But I'm calm!" She goes, "Has nobody explained to you what happened?" I'm like, "No." She goes, "Well you had an MI. Yesterday when you did that barfing thing, that was your MI." I'm like, "What? Like, an MI like a heart attack?" She goes, "No, not *like* a heart attack. A heart attack, exactly."

AS: Actually a heart attack.

JC: Yes. "You had a mild cardio infarction, and from what we can see, an eighth of your heart is dead."

AS: And was it just luck that they got you in early enough to get the blood work done?

JC: Well, I had already had the heart attack. No, the cardiologist said to me, "If you'd known that this wasn't heartburn, if you'd come in with all that big pain, if you'd taken an Aspirin and got here we could have stopped the heart attack." But it's just nobody thought. And of course, the symptoms of a woman having a heart attack are very different. Both arms, shoulder... and when they showed me this chart of the wave, the swoop of pain across your shoulder, it was exactly—like, "Oh yeah, like right into my jaw!" Yeah. But you know, again, they were seeing it in the States and in other countries, but they just weren't making the connection here. So the treatment has kept me alive. I'm 60 years old. When I was... what was I, 33? When I was diagnosed they said, "If you're lucky you'll have 12 years." I mean, initially it was six months, get into clinic, they say, "No, 8-12 years, most likely 8, you'll get your kid through school." So this next month will be, I think, 27 or 28 years since I've been diagnosed. It's the treatments. I mean yes, there are a handful of people around the world who are non-progressors, and have lived as long without treatment. But for me, even when it was monotherapy back in the AZT days, I mean I just "woosh," really fast, like less than six months after I was infected, not even diagnosed, six months after I was infected my T cell count was below 200. Now my T cell count is, I don't know, 900 or something? Which is kind of that of a woman who would not be infected. I have an undetectable viral load. And even the meds I take today, in part because I'm resistant to many of them ... I guess, probably by about 2002 I was on salvage therapy, which is, they're recycling drugs, I was running out of options. And research in the field of treating HIV has been so fast, for all kinds of reasons, it's really lucrative is one reason. In 1989 there was one treatment. When I tested positive there was one treatment. Now, I don't know, there's like 357,000 combinations of treatments. And I guess I would say that for me, for probably the last ten or fifteen years, the hardest thing for me about living with HIV now are the treatments. You know, the heart attack, the damage they've done to my teeth. My teeth literally are falling out and breaking and having to be pulled, and other dental work needs to be taken out and

can't be replaced. I'd say probably in the last two years I've lost four teeth, and I'm in the process of having a plate made, simply because, you know, I talked about having implants done, which are about 4 or 5000 dollars each. So right now I desperately need two in order to protect one tooth, so I'm looking at having to come up with 5 or \$10,000. But my front teeth are going, so do I just – 5, 10, 15, 20, 25 – you know, what, I'll spend \$90,000 on implants? And many people within the AIDS community are seeing loss of bone density, so then x-rays already show I've had some of that, oral bone density loss. So, would the implants even stay?

Back in '91, where I thought getting my kid through high school and *maybe* making it to the end of my 40s would be quite a feat—well, not even the end of my 40s, my mid-40s. These are things we didn't think about. And because we didn't think about them, we couldn't even imagine reaching an age where, historically, we would have started losing something like our teeth anyway. So it's really shocking. I think probably, I was my HIV doctor's first ever patient. I was his last patient when he retired, after a 25-year career. I outlived his career. We were very, very close. I mean, there were times he cared for Randy. With HIV, I suppose with other illnesses, but with HIV, a kind of intimacy often develops with your physician. It was really awful, that day. We probably spent about three hours together. We just reminisced, and we laughed, and we cried, and we talked about people that have died and you know, people whose bedsides we both were at. The clinic staff would come in and they'd take one look at us and start to cry and walk out. And I think his whole last clinic was like that, you know? Probably his ten patients who were there kind of right from the start. It was just a very, very different ending to our relationship, to where we thought it was going to go. The couple of years, two or three years now since he retired, have really left me sort of thoughtful. As much as I've talked about it in the past, that "Oh yeah, I didn't make any plans for my old age or anything," you know, none of us did – people cashed in their life insurance policies and did reverse mortgages on their homes, and I'm lucky with compensation. Many people of my age who are still alive have no assets. They're destitute and they're facing things like, "Well, where am I going to get five grand to replace a tooth?" So, I think when I realized I outlived him, I realized that I've really been taking unawares that I'm still alive and that I'll keep being alive. That's around the same time that my marriage ended. So, to be in my late fifties, facing the same kind of thoughts I had after Randy died, like, so, it's the 90's, I'm in my thirties, and of course you know, it wasn't like we cremated him and I thought, "How am I gonna get a date tonight?" As time went on I started thinking that, like I'm probably going to be single for the rest of my life. Which I wasn't.

At first when my doctor retired, I felt really old, and I felt really decrepit. I guess it just triggered something—like, no, no, I'm supposed to go before you. I'm supposed to die before you. It kind of felt like an undead dying that I went through. I suspect with a lot of us old-timers, if you can get the conversation to go there, I suspect probably a lot of people have done that. And it's not even learning how to live again. For my 40th birthday I went skydiving. For my 50th birthday it just felt like this rebirth; I certainly never expected to be 50. I did a complete body shave. For my 60th I'm like, "Well, what am I going to do? How would I top that?" and I just realized, I'm not going to do anything, because a milestone – I just actually wrote this to my friend the other day – that's the paradox of being a long-term survivor, is we're reaching those milestones, but they're so much less important. It's so much different than the milestone of being 40. It's not that I feel like I'm old, or I'm just not going to have a life. I feel more vibrant now, probably than I even did in my 30s or 40s.

And that was it. Like, I just spent it with my family, with my son, and we just went to my brother's house and his wife, and it was just a family dinner, and I really just remembered all the people that didn't get to hit 60... the people that did [crying], and the people that are going to. And it's just so appropriate to me doing this now, because that's what I realized. That because of us, I got to 60. I didn't do this myself. Because of us, I got to 60. Because of us, I'll probably get to 70 and more. I guess, for all the fighting and the insanity and the lunacy, I found my people, and I found my home and my community, whether I'm part of it or not. It's kind of like when you grow up and go to university and you move to Vancouver. You always know you can come back to Nova Scotia, but you live in Vancouver now. That's kind of what it feels like. My community is still there if I need them, but in a way, we've all just been set free. And that's what we were able to do for each other. We were able to – all of us set each other free. [crying]. Woo!

AS: That's beautiful. And it's really true. It's something that we reflect on a lot, just the incredible beauty of people fighting for life collectively.

JC: Well, and we were kids! I was 32, 33 years old. Like, I should not have been thinking about death. I shouldn't have been thinking, "How am I going to nurse my husband to death? How are we all going to care for each other?" Like, we were in our 20s and 30s and 40s, we should never have been thinking of that. And that became two decades of our lives, 20 years of our lives, to think about dying or to deny dying. I mean, we did so many positive things, people living with HIV, and all the variations of names we went through, and our declaration of human rights of people living with HIV, and for me, I always was just in denial. For all those years, "Oh, I'm not dying of AIDS! I'm living with AIDS!" and all those phrases that I said, intellectually I believed them, but there was a disconnect between brain and heart. Probably I would say it more for people who were listening, than to really believe it myself. Then when I did believe it, then it became like I had to work really hard at being alive. And it was way too tiring. You know? Jumping out of planes to show them I'm not afraid of anything [laughter]. I'd rather move to Annapolis Royal and buy a farm and grow some beans. [laughter]

GK: Well I think that sort of also answers the last question I was going to ask, which is the significance of AIDS organizing for you. Unless there's anything more you wanted to add.

JC: I'm pretty sure I can't top that. [laughter]

GK: Okay. So that's great. So I think maybe we can turn it off now, unless there's something that's cropped up as we've been talking that you haven't had a chance to talk about that you think is important to say.

JC: You know, the one thing that we didn't really talk about were issues around women having children. And some of the changes that we made, even in terms of treatment, when I was with CTAC we were at a meeting with... so, CTAC was a national organization that was half funded by a group of, I think, five pharmaceutical companies, and half funded by the federal government. So, we worked very closely with the pharmaceutical companies, but we also, because we were funded by the federal government, could pick at them and criticize them, and red tape their booths at AIDS conferences. But I remember one of our early conferences, where we were talking about

women in clinical trials and women's health, and trying to explain it to this panel discussion. And you know, there were several women. So, they kept bringing every issue back to childbirth or pregnancy or treatment for children, which are all very important. And I finally said, "But what you're failing to understand is within the AIDS community, just like any other community, there are women that don't even like children!" One of the women on the panel looked at me and goes, "What do you mean?" [laughter] I'm like, "Well, not every woman in the world lives to have children! Lots of women don't want children. So, all this palaver about, 'Oh, take this drug and your baby won't be born positive,' that's all great, but that's HIV prevention. That's not treatment for women. That's two different things." But you know, I really do think that Canada was a leader in that kind of movement. I think ACT UP in the States, was doing some of that. But the other thing we accomplished in terms of just treatment for everybody—so, initially, you'd go in a clinical trial. The trial would run its course; they were usually pretty quick. And then, once the drug was approved, you didn't get the drug anymore, unless you had a way to pay for it. So, there actually was a meeting, I think in Moncton, where we reconvened the meeting with drug companies, and that's when we started saying to them, like, "You treat your lab rats better." You take the drug away, but you keep feeding them, you keep them alive. You give us a drug that rejuvenates us, and we prove for you that it works, and it's viable, and you'll go off and sell it now and say, "No treatment for you!" So, actually, the pharmaceutical companies in Canada changed their policy, and that is just without question, every drug trial now the drug continues to be provided for you, if you wish, until there is another payer available. That was early, really kind of cutting edge stuff. The stuff around inclusion of women in trials. The other thing we really fought over was the ability for parents, and often, in particular mothers, to make treatment choices for their children, and to decide when to start treatment, when to stop, if to stop, and maybe not start at all, maybe do alternative treatments... women were losing their children in Canada for not treating them with drugs. There was very little data available on dosing kids. That was one argument we used in terms of clinical trials for women, like, we're all being overdosed. Lots of us are half the size of a man. So then there just wasn't a lot of good research available, in part because, presumably, there were not that many positive kids, or many of them were very, very ill shortly, within a couple of years. And that was in part of the declaration of rights for people who are living with HIV, that we came up with. And we worded it very specifically—we were demanding the right for parents to be allowed and empowered to be the parents to their children, that the state was not going to parent the child. And I think maybe 40% success within the medical community. I honestly can't say what level of success, but I think a lot of doctors, at least in major centers, heard that. And there are clinics in Vancouver that are one-stop for the whole family, so mom, dad, the kids, everybody goes in and gets treated together and everybody's making the decisions together.

The thing we missed out on, I remember being in some of the discussions, it was late in this decade, discussions around children who are born positive and now are dating, and what kind of educational programmes need to be developed for them. And we now know of kids, the foundation in the States... the star of Starsky and Hutch... Glaser. The Elizabeth Glaser Foundation. So, yes, their son Jake was born positive, oh, in the early '90s, and Elizabeth died, her daughter died, and their son is like 38 years old, born positive, and he runs the foundation. So I mean, those were just things—if a kid was 9 or 10, every time we heard of a kid who turned 11 or 12 it was like, "What? A 12-year-old kid that was born positive?" So, and I mean that is being addressed now. I think in part just a lot of the kids are addressing it themselves. There's a whole new

generation of very different activism, because they've grown up with the Internet, and the history that some of us laid the foundation of, which of course, the foundation I stood on was a history that was already created.

GK: This has been quite wonderful.

AS: Yes. Thank you so much.

[END OF TRANSCRIPT]