

# **A C T U P O R A L H I S T O R Y P R O J E C T**

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Interviewee: **Karin Timour**

Interview Number: **015**

Interviewer: **Sarah Schulman**

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00:01:51           **SARAH SCHULMAN: If you could say your name, how old you are, today's date and the address of where we are?**

KARIN TIMOUR: Okay. My name is Karen Timour, I'm 42 years old, and we're at 81 Payson Avenue, New York, New York.

**SS: And today's date is?**

KT: Is April 5, 2003.

**SS: Okay, great. Karin, do you remember the first time you heard the word AIDS?**

KT: Yes I do. The first time – well, I don't – do I remember the first time I heard AIDS? I don't know that I remember the first time I heard AIDS. I remember when I heard about this disease that was killing gay men. That I do remember.

**SS: And who were you at that moment?**

KT: I was an American traveling in Europe. I was in East Germany, and I had actually crossed over into West Berlin and was staying with a German doctor, who was actually an East German doctor. He was the fiancée of a woman I'd met on a train, and she said, oh, well, you need someplace to stay when you're in West Berlin. You stay with my fiancée. So, I stayed there, and he had English language newsmagazines. And, he was talking to me. And, he had a subscription to Time and that was when I heard about this gay cancer thing.

**SS: So, when did it first come into your life?**

KT: It first came into my life when I was living in Brooklyn, and my landlords were an African American gay couple, and they had been together for about 10 years, and

their dream was to own their own home. And they bought a handyman special in Brooklyn, fixed it up to some extent, rented out the top half and I and several other women rented the top half of the apartment from the – of the building, and they lived in the bottom two stories.

And, one of them got sick the fall we moved in, and he got steadily sicker and sicker. He was in the hospital almost continuously from late August until December. He came home for Christmas and then went back into the hospital. He died the following May.

**SS: What year was that?**

KT: That was – I believe it was 1985.

**SS: So, what kind of care did he get?**

KT: I think it was – well, he primarily was in the hospital. I mean, it was in the years before people were being let out. People couldn't live, really, independently. His lover would nurse him when he was home, and they had – when he finally died, they had a ton of all the nursing equipment – they had fusion pumps and the – all that stuff. And when he died, his family, who had been very unhappy about him being involved with a man and had always felt that the other one had turned him gay and this, that and the other – he died without a will, and they came in and made a very good attempt to steal the house away from his lover – took the whole thing to court, refused to let him go to the funeral and so a bunch – the neighborhood that I lived in, in Brooklyn – we were very tight.

**SS: What neighborhood was it?**

KT: It was on Dean Street, between 4<sup>th</sup> and 5<sup>th</sup> Avenues, and it was just starting to gentrify. And, so, there was this, sort of, very pioneer flavor. The prostitutes used to bring johns onto our street and we were trying to discourage that and that sort of brought the neighborhood together. So, we were trying to negotiate with the prostitutes to encourage them not to come onto our street because that also brought drugs and it brought a lot of other stuff. But, literally we were one block over from a neighborhood where there was a lot of active prostitution and a lot of drugs. And then – so then, he went to the – we took him to the funeral. There was this whole scene at the funeral. His lover was sealed in a coffin under glass. It was an open casket, but he was sealed in there.

**SS: Because he had AIDS?**

KT: Yeah, yeah. There was a whole screaming scene out in front of the church, because he wanted to go to the gravesite ceremony, and the family basically said that they would call the cops if he did. So, we took him home. While we were at the funeral, his mother-in-law had had the gas, electricity and water disconnected from the house. So, when we got back from the funeral, he couldn't even have a cup of tea in his own house. We had no electricity in our apartment, so we went across the street and basically had a meal across the street. He got sick about three months later and died of kidney failure five months later. He also died without a will. He left this huge grieving family, who was furious about the way he had been treated in the last years – last year of his life. So, now we had these two families locked in this huge court battle over the house. And that was my first experience of AIDS.

**SS: So, your first experience of AIDS was an experience of profound oppression, cruelty, no rights – and that was your introduction. So, when did you decide to be active in the AIDS movement?**

KT: Well, I've been politically active since third or fourth grade. I read about ACT UP in the New York Times Magazine. There was an article in, I want to say, '87 or '88.

**SS: By David Leavitt.**

KT: It might have been, yeah. And, it was talking about this group that actually got things done – things changed. He told the whole story of fight to get the airlines to let people with AIDS fly. And, I thought, wow, a group that's not only politically active, but actually gets things done. And, that was when I decided -- I said, okay, as soon as I finish graduate school, and I have a little time, I'm going to go down and start going to meetings and see what it's like.

**SS: What other movements had you been involved with?**

KT: Oh, I mean – see, I always thought that political activity was sort of – it was an important thing for a person to do morally. It's like your rent for being here. So, I was a member – when I was in fourth grade, I joined the Women's International League for Peace and Freedom. And it was me – in central Indiana, this is not a big group – and it was me or four or five really old ladies, sitting around a folding bridge table, writing letters about the B-1 bomber, and mailing those off.

I had been a feminist, literally from grade school, fourth or fifth grade. I decided I definitely was a feminist. And, I got involved – there were a lot of smaller things that I was involved in through high school. But then, when I went to college, I got involved in

the divestment to try and get – I went to the University of Michigan and we were trying to get the University of Michigan to divest the funds that it held in South African companies. And, we actually did get them to do it, which was such incredible reinforcement. We also fought cruise missiles. I remember nuclear warheads on submarines. The draft was re-instituted while I was in school. There were a number of things that I got involved in when I was in college.

**SS: So, what were you studying in graduate school at the time?**

00:10:00

KT: I was going to Columbia – to Teacher’s College, and I have a Masters of Arts in Psychology and a Masters of Education and Counseling in Counseling the Culturally Diverse. I wanted to work – I’ve always been fascinated by culture. There are five different cultures in my parents’ generation – my mother’s family. And so, I always was surrounded by people from very different backgrounds, and was always really fascinated the way that culture dictates your perceptions, and that culture helps to define what you see as important in the world.

And when I first came to New York, I decided fairly early, that what I really wanted to do – that one of my important life values was to help things be better – that it was important to me that my life be used to make the world a better place, and that somebody’s life be better because I was here. And so, I decided to go to graduate school. And I wanted to be a mental health professional, but I wanted to help more than just one person at a time. So, that’s what I went to graduate school for.

**SS: So, then you just went down to the [Lesbian and Gay] Center?**

KT: Yeah.

**SS: To the first ACT UP meeting? Had you ever been to the Center before?**

KT: No, I'd never been to the Center before. I knew where it was, but I'd never been there before.

**SS: Had you ever been to a gay community event before?**

KT: Oh yes, because when I was in graduate – when I was in undergraduate school, I was a residence director. I put myself through school, and one of the jobs I had was being residence director. And, I remember, distinctly, because we had to go through gay sensitivity training. And so they – we played this whole game where you had to name all the different names for gay people.

And then, I also – when I went to school, I went to the University of Michigan, and within the University, I went to a part of the University called the residential college, which was designed to be a small liberal arts college within a larger university. There was a very high proportion of gay and lesbian people there – and that's where I really first started to meet gay people. Or, gay people that I at least knew and who were out.

**SS: Why do you think you chose to make your stand with gay people and people with AIDS?**

KT: It was because I was already working with AIDS. My first job was as an HIV coordinator within in-patient drug rehabilitation.

**SS: Where, at what facility?**

KT: Phoenix House. I was hired at Phoenix House as one of the first HIV coordinators. When I was finishing graduate school, the federal government made it one of the requirements, if you were going to get federal funds for drug treatment, that you

provide HIV services on site, and I was one of the first waves of HIV coordinators that were hired to provide HIV care within outpatient drug treatment.

The other thing was I had – the final year of my graduate degree program, out of the 40 women in my graduating class, four of them found out they were HIV positive, the spring that I graduated. And that was when HIV really came home for me because I had always believed before then, it was gay men and IV drug users and that was very sad, but it didn't have very much to do with me. But, these were white, middle class women with no history of drug use and no history of transfusions, and that was when HIV really came home for me, because I knew that I'd had sex with[out] a condom in the previous 15 years, which meant that I was at risk.

So, I started doing a massive reading on HIV and then I read the David Leavitt article, and I'd already had this one experience, because my frame of reference was this terrible experience that had happened in Brooklyn and my landlords. So, it just seemed very immediate. It seemed like something that could potentially happen, and I think – I hadn't been tested at that point – and there was a part of me that was really frightened that maybe I would be positive. And, it was, okay, get busy. Because I already knew that the state of healthcare wasn't what I was going to need, if I was going to be HIV positive.

**SS: So, what year was this that you first came to ACT UP?**

KT: 1989.

**SS: '89. So, when you walked into that room, what did you see?**

KT: I saw a lot of gay men, a lot of gay men. And, it was really interesting because, practically nobody talked for me for I would say a good, I would say, probably,



00:20:00 the first three or four months that I was going to meetings. But, I just learned a lot. I wrote – did a lot of note taking. And, the other thing that happens that sort of ties into starting to go to ACT UP – I went to about three or four meetings, and right before I started going to ACT UP meetings, my brother got diagnosed with something called Marfan Syndrome, which is an inherited disease of the connective tissue. And, he was just finishing undergraduate school, and he didn't know whether he'd would ever be able to be employable, because Marfan Syndrome is – what usually happens is that your heart and your aorta get larger and larger and then they rip and you bleed internally and you die. So, you have to have surgery to slice off the top of your heart, and replace your aorta and your mitral valve, and he – when he got diagnosed, his aorta was six times normal size. So, he was freaked out. He was really worried about – would he be able to get a job? And, I didn't – I'm not a math or science person. I really don't understand math or science. I can't work in math and science. But, I understand how to read and I'm a really good researcher. So, I went to the College of Insurance in downtown Manhattan and started trying to read everything they had on health insurance, to help my brother, and help him to understand what his options were.

And then, I was going to ACT UP and after I'd been going to ACT UP for about six weeks, they announced they were going to start this health insurance committee. And, I was, like, wow, maybe they could help me, because I wasn't making a lot of headway at the College of Insurance. So, I went right over and said, okay, I'm really interested. Where's the committee? What do we do?

**SS: So, what was the state at that time, for people with AIDS, in terms of insurance?**

KT: Well, it wasn't really great. There was – Empire Blue Cross and Blue Shield had something called the million-dollar policy – the million-dollar plan, or the million-dollar policy. And, there was an open enrollment period every year. I believe it was only a month. And during that month, you could get this particular policy. But, nobody else was insuring people with chronic illnesses. And, if you missed that month, then you didn't have health insurance.

**SS: So, at this point – was the committee created out of the needs of people in ACT UP? Were there people with AIDS in ACT UP who could not get insurance?**

KT: If there were, they didn't come out and identify themselves. It was people who said, we need this, we want to do this, let's start learning about this. It was funny, because [Larry Kramer] came to a couple of the first insurance committee meetings, but, what we decided pretty quickly was, there's a lot of information we need to master, before we're going to be able to go out and do anything. And there were actually some insurance professionals, who were among that first group. And then, there were also people who knew people. And so, we had this whole series of teach-ins and we started just reading documents and learning about how is health insurance structured. We did some stuff about life insurance, too. But, we were really, really focused – we didn't spend – in the first, I would say, six months to a year, we didn't spend any time at all on Medicaid. It was all looking at private health insurance.

**SS: And who was in the committee from the beginning?**

KT: Bob Padgug – who, at that time, was working for Empire Blue Cross and Blue shield.

**SS: How do you spell his name?**

KT: Padgug – P-a-d-g-u-g. Myself. After we'd had about two teach-ins – at the third teach-in, this extremely strange character showed up, wearing a straw hat and a bandana and that was David Peterson. And David Peterson – among a whole range of people – changed by life.

David Peterson was a private financial planner, and he always – he was very proud of being the mid-wife of the viatical settlements movement. And he was one of the people that actually helped to figure out how you could sell your life insurance. And he came to the meeting. I remember, he came to the second or third meeting and he said, you shouldn't be having these workshops. I'm writing a book about this. You should just buy my book. And everyone was, like, who are you? Go away. If you want to sit and learn, sit and learn. If you want to share information, share information. But, don't tell us to all go away and not do anything. And so, he just stuck around. And he was one of those people who was – like when you were in high school, the person who would always correct the teacher, and they were right, but they were really snotty about it? That was David. Wayne Kawadler was in the insurance committee from very early; Barry Lapidus was, as well.

00:20:00

**SS: Is that Wayne with a "K" or a "Q"?**

KT: Wayne with a "K" or a "Q"?

**SS: Wayne Kawadler?**

KT: It's a "K" because – it was really funny, I never really know how to spell it, and for one of our demonstrations, much later – the one about the air traffic controllers' disability coverage, I sent to – I was in charge of putting together letters, but

he decided to sign them, because, at that point, he was the chair of the committee. And, so, I misspelled his name as “Wayne Kwandler,” and sent out letters to every single insurance commissioner for every state and every U.S. territory. And so, we got correspondence for years after that to Mr. Kwandler.

**SS: So, what did you guys decide was your first goal?**

KT: Our first goal was to get a stop loss in the Empire Blue Cross and Blue Shield – the brand new – Empire Blue Cross and Blue Shield had just come out with this brand new product, which was an open enrollment. So, that meant that anybody could buy it. There wouldn’t – they wouldn’t discriminate between the well and the sick. They’d come out with an indemnity policy, which meant – it wasn’t an HMO – it was one of those old fashioned kind, where you’d go and choose any doctor you wanted to. But, they had forgotten to put a stop loss in.

**SS: What does that mean?**

KT: Well, that’s easier to explain with a chart and a magic marker. A stop loss – most people when they start using their health insurance – you have a deductible, so for a certain period of time, starting in January, you have to pay 100% of your bills, and you just send them into the insurance company, and they don’t pay you anything. And then, after – you can do a certain point – usually \$500 or \$1,000. You’ve met your deductible and then they start paying 80 percent of what they think the bill should be – not 80 percent of what the bill is, 80 percent of what they deem usual, customary and reasonable. And then, they pay 80%, you pay 20% for a certain period of time. And then – and it’s usually – in most cases, it’s, like \$10,000 or \$15,000. When you’ve got \$10,000 worth of insurance claims in one year, that’s when you should hit your stop loss.

And, at that point, they pay 100%. When this product first came out on the market, they'd forgotten to put a stop loss on it. So, that meant you would pay 80%, until you ran out of money and went on Medicaid.

And so, it's a fairly technical thing to get across in a demonstration and sound bytes and things like that. But you have to also understand when we were doing activism with the insurance industry – this is a fairly stuffy industry and they were really not ready at all for ACT UP to come and do demonstrations. So, we did a demonstration. There were six of us, maybe – with signs – in front of the Empire Blue Cross and Blue Shield building, which was a city block wide – huge – didn't really have a clear entrance. The entrance was halfway into the block. You had to go into this courtyard, and down this hall and so, we stayed out on the sidewalk. They had a sign, right at the corner of the street of Third Avenue and, I think, it was 40<sup>th</sup> Street was where it was. So, we just marched in a little teeny circle so we would be right in front of the logo for Empire Blue Cross and Blue Shield. And they were just blown away that we were out there. And they immediately invited us into the building – please come in, we'd – they just didn't like the whole idea of –

**SS: Did they know who ACT UP was?**

KT: No, they had no clue. So, they invited us in and we said, we can only negotiate if they would put a stop loss in, and the next week, they put a stop loss in. So, that was the first piece. And then, the other piece was that we – one of our other demands was that they put in writing that HIV was not a pre-existing condition – that they would only consider AIDS a pre-existing condition. And, they came to on that, too. So, those were our first demonstrations from the insurance committee. Those were the

first things that we worked on. And, it's very heady when you start out and there's six of you with foam core signs, and you win.

**SS: So then what happened when you started to have these victories? Did the rest of ACT UP notice what you were doing?**

00:25:00 KT: I don't know that they – I know it's not a wildly, sexy, fascinating topic – but we just set out to start educating them. So, it was every time we had something that we wanted to do, we had to get up and do a little teach-in about what is this thing? What is a stop loss, and why do you need one? Then, we would just keep getting up and say, okay, it's coming – our demonstration is six weeks from now, five weeks from now, four weeks from now, here's the – and we'd get the approval of our fact sheets and things like that. It was just – it was a whole thing about – you need this, we're going to do it, but we're real tiny, so when we need the troops, you guys gotta come. And that – that was really how we functioned, largely – was that, we always were a very small committee. I don't think we ever had more than 10 people come to a meeting. But, we were just – we were like the little action core – do the research and find out what the thing was and then, go to the floor, explain it to them and then they would show up.

**SS: And they would show up?**

KT: Yeah.

**SS: So, then did you start to find that personally, people would start to approach you and ask you questions about their insurance issues?**

KT: Yeah.

**SS: And what were some of the – what was the range of insurance issues of the people who were in ACT UP?**

KT: We actually did this survey of the floor one night. We did a survey to find out what insurance – did people have insurance? We found out that a third of the floor had no insurance.

**SS: A third of ACT UP had no health insurance.**

KT: Right.

**SS: That's very interesting because there's a stereotype that ACT UP was made of wealthy people.**

KT: Well, it was made up of a lot white gay men, but a lot of them were cater waiters and actors and photographers and people who didn't necessarily have a huge conglomerate they were working for. Temps – temporary secretaries. There were some – there were definitely some people that had very nice jobs that were in ACT UP, but there were a lot of people that didn't.

**SS: So, did your committee – did you have a big picture agenda? Did you have a big goal, and then you would make little steps towards it? Or, were you just learning the field, as you were going?**

KT: Well, it's funny – things would kind of – actions would kind of come to us. We were learning the field. There was a huge area to learn. We got subscriptions to the insurance industry trade journals, and, for years, we had a subscription to *National Underwriter*. And, actually – when we would throw demonstrations, we would send press releases to *National Underwriter* and would remind them, we're subscribers, and we're having a demonstration and we expect you to come and cover what we're talking about.

**SS: Did they cover it?**

KT: Yeah, yeah – sometimes – so, it was really funny because everybody else would do a demonstration – they would have drug company – they would be sending out press releases to drug industry newsletters. We're sending things to *National Underwriter* and all these insurance company trade rags, in addition to the *New York Times*, this, that and the other. So, every so often, we would get someone from the –

**SS: So, when did you first get resistance? I mean, there must have been a point where they were, like, we don't want to be controlled by you or your agenda.**

KT: Oh – I mean, the insurance industry, by and large didn't want to ever be controlled by our agenda. We were – it was always a case of we're the mosquito, and we're just going to keep nibbling away and see what we can get. And the thing was that, because they were so unused to having to deal with this – this was not – it's a very stuffy industry – insurance, by and large – that –

**SS: Can you give me an example of where the industry resisted?**

KT: Oh sure. In – I forget – I think it was in 1990 or '91 – I don't remember, the National Air Traffic Controllers Organization [Association] [NATCA] – basically, the union that came in after Ronald Reagan got rid of PATCO – they wrote into their disability coverage that if you got AIDS because of drugs or sex, the disability insurance wouldn't pay anything, but if you got it through birth or blood transfusions, you would have full disability coverage. So, we decided that was discrimination and that was outrageous. And, so, we started learning about disability insurance. It was okay, how can we – we would get a topic or a subject, and then we would start trying to figure out – okay, now, what do we need to know to understand about this? To figure out a way to turn this around? And, so, it turns out that when – that the particular way that disability



insurance was written – when it’s a thing like that, where it’s national – because insurance is regulated on a state by state basis, that there isn’t a national, really a national insurance anything. Or, there is, but, most things having to do with insurance are regulated on a state-by-state basis. So what happens is that there’s a master policy that’s filed in one state, and then all the other states just file a duplicate of it. Well, we didn’t know what state had the master policy for NATCA. So, we filed formal complaints charging them with discrimination on the basis of disability in all 50 states and all the U.S. territories – Guam, the Virgin Islands, etc. So, we sent out this letter saying – asking the commissioner of insurance in all these different states to check and see whether their state disability laws would make it problematic for them to have a union that was discriminating on the basis of a disability. And we filed formal complaints in all these different states. And a lot of the commissioners just were, just filed it in the circular file. It was just, who are you? Leave us alone, we don’t need you. But, I’ll never forget, we got Kentucky, West Virginia, Arizona – all said, yes, this has merit. And then, what really turned it around was when Illinois said, yes, this is a problem. And what rapidly became clear was that NATCA was either going to have write two different disability policies – one for the states that did find it a problem, and one for the states that weren’t – or we’re just going to have to change the whole thing. And that’s what they did. They changed the whole policy.

So, it was that kind of a thing, where disability interest was not our major focus, but this was a problem we went out in and started working on it, and it meant, having phone calls with insurance commissioners; talking to them about why we thought it was a problem and sometimes we won and sometimes we didn’t, but that was one that we did.

And it was every air traffic controller in the country who got HIV and who eventually got AIDS got the full disability coverage no matter how they got it, because of something that we did. And that was just, like, wow. If you've spent your life sending letters off against the B-1 bomber and having it get funded anyway – to then have three or four or eight of us, with the help of all the ACT UPs in the country, because we would then – we would do things like – we would send the same letter off to all the different ACT UPs and say, please file similar letters. So, it was sort of being the computer geek or the AV geek or something in your high school. I mean, you're the insurance geek and in all the different ACT UPs there were – in the larger ones, at least, there were usually one or two people who were – they were the insurance geeks, too. So, I remember distinctly, there was a conference in Chicago of all the different ACT UPs and we went and had a little workshop on how to do insurance activism – what have we learned, and what have you learned? And it was sort of everybody sat down. There were maybe 10 of us. And, it was okay, this is what we did that worked, and what have you done? And then it was, from there, whenever we had an issue, we could send off a letter to the guys in San Francisco and say, here, get this out and get all your chapter to do it, too. And there were two or three in San Diego and there were a couple of guys up in ACT UP/Washington who helped. And it was – then, there was a little group of us that could – they were doing health care access issues, and we'd share stuff back and forth.

**SS: What were the most effective strategies in dealing with the insurance industry? And, which strategies did not work at all?**

KT: The most effective ones? Well, filing a complaint against – in the insurance – in each state with the insurance commissioner, that was pretty effective.

Something that – I mean, some things you didn't get a fast return on, but you got to develop real change. With the open enrollment community rating law – that really made change.

00:35:00 One of the things that – in terms of – one big thing was to get – to organize people with chronic illnesses and have them tell their stories about insurance. That's – whenever you're discouraged about how are we ever going to do this or what's going to happen? I would always go back to the fact that insurance, for most people, is a real snoozer. When you start talking about insurance, a lot of people go to sleep. But the thing is, when you start talking about insurance in terms of money to pay for your care, everybody's got an insurance company horror story – everybody does. And if they don't, personally, they have someone that they love who does. And, so, when you start talking about it and start talking about it in that kind of frame, people galvanize. They understand what you're talking about. This is very real, it's very concrete. When I was in college, I took a course once on trying to understand socialism, because I didn't know anything about socialism. And, we had to read Lenin's *What Is To Be Done* and the professor – I'll never forget it – I didn't learn that much about socialism, I wasn't that good of a scholar, but this professor said, think about, if you're going to do a revolution, what is going to get people to leave their job, go out in the street, and confront soldiers who are armed with guns? What is it that's going to make people – it would be so concrete and so real that people would say, yes, I will stand up for this. And I always remember that. And, in terms of community organizing, it was you have to make this real for people. And health insurance – one of the things that always – I always used to say was that, when it comes to health insurance, by and large, the insurance companies are our biggest allies because

they – especially the HMOs and managed care and this, that and the other – people have a real feeling, a real experience when the doctor tells them, no, we can't have that treatment; no we can't pay for that. People remember that. That's visceral for people. And that always – if we could make it real for people – that this could happen to you, do you want this to happen to you or someone you love? That would really move people, and that really worked.

**SS: So, there on your lap there, is that a list of all of your actions?**

KT: Yes.

**SS: Tell us about some of them.**

KT: Oh, Lordy, let's see. We started out as just the insurance committee, and then we became the insurance and healthcare access committee, because there was a small group that got themselves organized and said they wanted to do Medicaid. And, I don't know if you remember Natasha Gray –

**SS: Sure.**

KT: Natasha Gray was one of the people that had this little group and they all kind of coalesced and said, they came to our meeting and they took over our meeting and they said, you must deal with Medicaid, you must deal with public entitlements. And, we were – we've got enough on our plate with insurance. But then we started looking at Medicaid things and – I don't know how much you know about Medicaid – but, basically Medicaid and state school aid are the two big things that the state legislature spends its money on every year. And, every year in the spring, when it's time to make the budget, there's this whole piece around, do we cut school aid, do we cut Medicaid? What do we do? And one year, the legislature decided that people with chronic illnesses were

enjoying spending time at the doctor way too much, and they would go too many times. And, they could go, because it was free. So, we were spoofing it. We said, oh yes, it's, do I go to a movie, or do I go to my doctor? Let's go to the doctor. And so, what they did was they put something in place called Medicaid utilization thresholds. And what they said was, that, if you had a Medicaid card, you get X number of doctor visits each year. And, when you get to your limit, you can't have any more doctor visits. And, you can have so many emergency room visits, etc., etc. And what happened was, that when that law went through the legislature – to change Medicaid in that way – there were a number of voices in the legislature that said, but, wait a minute, for people with chronic illnesses, they're going to need to go to the doctor more than that. So they said, okay. So, they wrote into law something called the override – which was, that your doctor – if you had a chronic illness, like hypertension, like HIV, like cancer, you doctor could fill out a one-page form, which would exempt you from the Medicaid thresholds. But, as is often the case, when that law went into place, they hadn't printed up the forms yet. And, once they printed up the forms, they didn't distribute them. It was hard to get a form.

So, what we did was – we did this action where we made reams and reams of forms. I mean, we did cases of Xerox paper of forms. And our thing was, that we distributed them on the floor of ACT UP and we said, everybody should take one of these. Give it to every single person you know who's got Medicaid, so that they have a form with them, in their wallet. It was sort of, like, have a condom in your wallet, kind of thing. It was have a utilization threshold override form in your wallet, so that when you get to the emergency room and they say, I'm sorry your Medicaid card isn't working because you've reached your limit, you can whip out your form and say, here's the form,

sign the form, and the doctor would have to sign the form. And that was – for years, we had – we would just, every so often, we’d just run off another couple of reams of forms, and put them out on the back table. Here, take these, and give them to people with Medicaid, because our goal – and we also went – and, what often would happen is that, you would reach your utilization threshold in the emergency room. And a lot of times the doctors that were in the emergency rooms especially for city hospitals were – they were interns and residents and all those people that were writing in their utilization thresholds in the middle of the night. They didn’t – where are the reforms? Who knows? Whatever. So, we would drop off chunks of the forms at emergency rooms for hospitals. So, that was one of the first –

00:40:00

**SS: But, how would you find out? Was it because there are people with AIDS in ACT UP, who are on Medicaid, who would tell you the situation?**

KT: Yeah, yeah. Or, there were people in ACT UP who were case managers, who would come and tell us, I’m a case manager, this is what my job is, I can’t do anything personally, but, if I were you, I would go and do whatever. There’s something that needs to be done about this. So, we’d go and research it. We’d get whatever information they had and then we’d go and run with it.

The absolute biggest win that we ever get in ACT UP all grew out of something that Empire Blue Cross and Blue Shield decided to do, which was, they decided in – I want to say, January – it was January of ’90 or ’91, where they were going to split the people that they insured between the well and the sick.

KT: I have to talk about Day of Desperation.

**SS: Oh yeah, that’s very important. Thank you for reminding me.**

KT: Yeah, we did some really fun stuff then.

SS: **Okay, so tell us – you were telling about the Empire –**

KT: Empire Blue Cross & Blue Shield decided to divide the people that were insured between the well people and the sick people. What had happened was that, because they were “the insurer of last resort” – because they had that million dollar coverage that people who had an illness could still purchase – albeit, only during that one month of open enrollment. What happened was that, basically, everybody who needed health insurance went over there and bought a policy – who could afford it. And what started to happen was that the cost of maintaining that coverage got to be higher and higher and higher. And so, Empire had to raise the premium. And as they’re raising the premium, what was happening was that, then the people who weren’t that sick would say, hey, my premium has gone to \$500 a month, or \$400 a month. I can go to insurance company Z and get the same coverage for \$250, rather than staying with Empire. So, the well people started going to other insurers and the sick people couldn’t switch. So – and, it was called – there’s an insurance industry trade term for it and it’s cherry-picking. So, they said that – because you pick the best cherries off the tree and you leave all the rotten ones to stay. So, basically what happened was, the chairman of Empire Blue Cross and Blue Shield went – filed for a rate increase, and at that point, if you wanted a rate increase on health insurance, you had to have a public hearing.

Now, we had discovered this about a year previous. We’d actually gone to a couple of rate hearings and given testimony about the impact of rising rates, but in the insurance – the Empire Blue Cross and Blue Shield’s rate hearings were traditionally held in a small room on the third floor of the Bar Association, in mid-town. So, it was usually

a pretty small room. There were, maybe, 10 people in the room, at any given time. So, they filed for a rate hearing, and they said they wanted to split the pool of people who were covered between the well and the sick people.

The well people would get a 20% discount, and the sick people – for the same exact same coverage – would get a 50% increase. And, we were just outraged, okay. So, basically what happened was that I took two or three days off work and I took a folding table down to the workspace and I set myself up. I had the phone and the phone book and my list of names and numbers and started calling all the organizations that represent people with chronic illnesses that I could find or figure out. The Heart Association and the Cancer Society – and, do you know what’s happening? Do you know what they’re talking about? Have you heard this? And David Peterson was independently doing the same thing and he had actually gotten something called the *Directory of Associations*, and was working his way through the *Directory of Associations*. So, we started talking back and forth – that we won’t do this independently. And David had the brainwave of let’s pack the hearing room. Let’s get everybody and tell them to come down and testify. And so, you had to call and reserve a space to give testimony. You had to call the insurance department.

**SS: Let me just ask you, had any of these other organizations ever been in coalition with people with AIDS before?**

KT: No, not that I had ever heard of.

**SS: And, did any of them not want to be?**

KT: Oh yeah.

**SS: Like which ones?**



00:45:00 KT: There were quite a few. There's a special place reserved for the Heart Association. The public policy director for the Heart Association kept saying things like, well, it will be interesting to find out what they decide. And it was yes, but this is going to affect people with heart disease and people with cardio problems and congestive heart failure. My grandmother, actually, had just died the previous year of congestive heart failure so I was very conscious of heart disease. And, I kept calling her and saying, let me just explain this a different way. Maybe you just didn't understand it. And she was, like, no, I understand clearly. It's going to be really interesting. I'm really looking forward to having a front row seat to see how this comes out. The Cancer Society – my father's parents both died of cancer and all of his life, he has raised money for the American Cancer Society – wherever we lived. When I was in grade school, cable television had just started and my father talked the local cable station into doing a telethon – a local telethon for the Cancer Society. So, they were one of the first calls I made and they made it really clear that, no, this was not something that they were going to be in coalition on, at all.

**SS: Did they say why?**

KT: They said, we have many other issues, and our legislative director will take it under consideration. They ended up coming down and giving testimony, but they wouldn't be in a coalition with us. One of the really surprising things was that, when I called the Hemophilia Association and – see, the secret story is that so many people with Hemophilia are infected with HIV.

**SS: Right.**

KT: And, they were on it like white on rice. They were absolutely – we will be there. They were just totally – and again they're a tiny organization. They were on board really early. Cancer Care, which is separate from the American Cancer Society – they said, they provide social workers and they totally understood what this one meant. So, they were on board really early. There were a number of transplant organizations that got it, and they showed up. And then, some of the AIDS organizations, as well. The problem is, we didn't want it to be 40 AIDS organizations, one guy from heart disease, and one guy from cancer, you know. So, we were trying to get, as representative – the Multiple Sclerosis Society – they were on board very early and they understood what this meant. And we just kept calling all the other ones. I remember the Tardive Dyskinesia Society in Queens – I was calling them and talking to them about coming down and giving testimony. It was every kind of obscure medical anything that I could figure out. I was reading the phone books to try and figure out what's another one that I could – what's a different. And I would ask them all, do you have any? – the Epilepsy Society, they were there very early.

So, what happened was, we started telling them, you can come down and give testimony and if you have one or two clients that want to give testimony, too, that would be great. Our goal is to pack the hearing room. By the time the hearing came around, they had – it had been – usually, for an insurance department hearing you'd have, maybe, 10 people show up, total, to testify. By the time we were a week out, we had 34 people or organizations signed up to give testimony. And they decided – then, we pointed out that, in fact, the hearing room was in the Bar Association and it was not a wheelchair

accessible space. And so, they moved it out of the hearing room. They moved it down the street, and they rented Town Hall Theater.

Well, in the meantime, we had, kind of, started meeting with our groups to kind of share ideas about how to do testimony, because some of them had never ever testified at an insurance department hearing before. We were also working on – and we wanted to have a demonstration out in front. And then, we were going to have some street theater and the actual hearings.

So, it was just – we were just wildly excited. And another group that was on, really early were the groups for the aged – the Brooklyn Interagency Council for the Aging, because one of the things that I – and that's all these different little senior groups in Brooklyn. They gave a coalition and they do political stuff. Well, now, when you're talking seniors – now, you've got a group that terrifies legislators, because seniors vote and they remember, and they care a lot about how much money it cost for healthcare. So, we decided we were going to have the Faceless Bureaucrats make an appearance – do you remember the Faceless Bureaucrats?

**SS: No.**

00:50:00 **KT:** Oh, the Faceless Bureaucrats. Well, working with insurance companies stuff, the Faceless Bureaucrats were very, very special. The Faceless Bureaucrats were an affinity group that would dress in business drag. They had paper plates for faces, with two eyes. And then, where the face – where the mouth should be, they had stamped – they had this rubber stamp that said, Faceless Bureaucrat. And they would show up, and they wouldn't say anything, but they would have signs hung around their necks that said things like, Don't Ask Me, I Just Work Here; Just Doing My Job; I Don't Know. So, we

talked them into making an appearance at the hearings. And, what they did is, they made signs that had the name, in very formal script – the name of each member of the team that was going to be testifying for Empire Blue Cross and Blue Shield, the Empire Blue Cross and Blue Shield symbol, and the words, Empire – We Don't Care, We Don't Have To. And they had those signs made up, and they also had the annual salary of each person across the top. So, there were four people who testified for –

**SS: Who were some of the people who were in the faceless bureaucrats, do you remember?**

KT: Steve Melvin was. I want to say Natasha Gray actually was, but I don't know whether that's true or not. I don't remember a lot of the people. When they were faceless bureaucrats, they had paper plates on. But, they came and there were four people who were testifying for Empire – doing the official Empire testimony. And so, we'd find out who they were, we'd research their annual salaries, we gave it to the Faceless Bureaucrats, so they all showed up. There were four people, who corresponded to the four, and they had the signs on. And what they did was, they went to the hearing, and when the hearing started, they stood up, and they turned in front – they walked down to right in front of the stage and turned and faced the audience and all the media, wearing the signs, with the – and, of course, it was right in the middle of Empire's testimony. Empire's testifying, the Faceless Bureaucrats get up and all the print media just rush the stage, because they wanted to get a picture of this. We also had a –

**SS: How did you get the print media there?**

KT: Oh, we told them. We explained the story to them and we told them that something was going to happen and they might want to be there.

**SS: Now, did you that? Or, the Media Committee of ACT UP?**

KT: We did it because the person who was in charge of the Media Committee explained to me that it's really hard to get reporters to cover something with insurance. They just don't understand it. And I was just so fried. I was spitting tacks, because it was – we'd organized this whole thing, we'd gotten all these people together, and now my own media spokesperson is telling me, no, it's just too hard. I can't do that. So, we got on the phone and we were calling and we put out our own press release and that was when I learned how to do a press release because it was, I'm not going to let this thing happen and have it not happen. We gave – we got morning television. Morning television came down and did interviews. I was standing on the curb, doing – "Good Morning America" came down and filmed us. We had a moving picket out in front. We had a banner that said, Insurance Discrimination Kills People With AIDS – KILLS, in giant red letters – wide as a city block. And we had the general ACT UP picket. So, we had people who were in business drag, on their way to work. And we had people in leather jackets, coming home from the bars. And they're all in this little circuit. And then, the school bus drives up, that's been chartered by the Brooklyn Interagency Council for the Aged. It's all the seniors, with their box lunches. They're coming for the hearings.

The thing you don't realize – or the things that I didn't realize, because I didn't grow up in New York was, a lot of the seniors – if you're a socialist when you're in your 20s and 30s, and then you become a senior, all you are is a slightly older socialist. And there were all these people on the school bus. A number of the senior groups in Brooklyn were made up of people who'd been very active communists and socialists, in their

youth. And so, they'd pull up in the school bus, and the school bus stops right in front of Town Hall Theater, and there's a picket line. They know about a picket line. So, they all bop off the bus, canes and walkers and the whole nine – fists in the air – and they just charged right in and got in the picket line. So now we had the leather guy, the guy in the suit, the little lady with a cane, and the guy with the leather. It was – it was just wonderful. And, they were, they were trying to learn the chants. So, they were chanting. And then, when it came time to go into the theater, the media all wanted to know, are you guys going to do civil disobedience in there? And we were like, you'll have to find out.

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And so, we went in, and we were planning to have the banner be in one of the side aisles, so that we could – while they were testifying, because when you do an insurance department hearing, the commissioner sits on one side, and he just listens to everything. And on the other side of the stage is Empire, and they open up – they give a slide show, they talk about how they need more money and they tell about what's going on. And then, they have a microphone set up in the audience and then, just group after group gets up and gives their testimony. They've all signed up for their spot. So, you have to sign up for your spot. So, we had the banner in the side aisle, facing the audience, saying Insurance Discrimination Kills People With AIDS. The two guys who were on the banner – it turned out, at least one of them was an Empire insured, and he got really – he'd never been to a demonstration before, but this was his health insurance. And, he just got really excited and so he said, come on, and so they leaped onto the stage and they held up the banner behind Empire, so that Empire had to give their testimony to all the television cameras and the print media in front of the banner that said, Insurance

Discrimination Kills People With AIDS. And the Chairman of the – the CEO of Empire, turned to the insurance –

**SS: What was his name, do you remember?**

KT: Oh yeah, yeah – Al Cardone. We nicknamed him Al, the Big Tuna, because he was – he had this blow-dried hair and this pinky ring, and he actually – there was a whole corruption scandal that came out very shortly after that. But, he was very – he was just sort of, exactly – he looked a lot like John Gotti, okay. So, he stopped when the banner leaped the stage and got up – and stood behind him. He was in mid-testimony, and he just stopped and he got this really pained look on his face and he turned to the commissioner of insurance and he said, Mr. Commissioner can you do something about this? And the insurance commissioner said, “Please continue Mr. Cardone.” And, we were in hysterics in the back. We were, like, YES. So, he had to give his whole testimony in front of us. And, halfway through, the Faceless Bureaucrats stood in front of him. So, he had the Insurance Discrimination Kills People With AIDS behind and the Faceless Bureaucrats standing in front of them. And they had to give this whole testimony about how they were – had no money, and this, that and the other.

And then we had, literally, a day and a half, of people getting up and talking about what it would mean for them, if this was approved. They went without a lunch break, without a cigarette break, solidly, hearing testimony from – I think we started at 9:30, in the morning. They went straight through, at 5 to 10 minute intervals. At the end of the day, at 5:00, we still had, maybe 60 groups to still hear. And so, they adjourned the hearing and resumed the hearings at the insurance department offices in downtown

Manhattan, two days later and had another half-day of testimony then. And we went to those hearings as well.

And, when we went to the second hearing, it was much more informal. It was very much smaller. The media wasn't there. And, actually, a number of people from the – from Empire – started confronting some of the members that were in our coalition. At that point, we had basically now formed a formal coalition.

**SS: What was it called, do you remember?**

KT: New Yorkers for Accessible Health Coverage. And we had a lot of discussion about the name, because we didn't want it to sound like insurance salesmen. But, we also wanted to make it clear that it was about – we weren't taking on Medicaid – that we were only doing private health insurance – that's what our focus was. And, the guy who was there from the Hemophilia Association was – he was essence of Brooks Brothers. He was – with the blue blazer, with the little gold buttons, with the French cuffs on his shirt, the whole nine. And, he's there, and one of the guys from Empire started picking on him, and he said, I can't believe you, from an established and respected organization would be sitting at the table with these. And there were three of us there. And – one was in leather, and one was in a skin-tight tee shirt. Then, there was me. And, I'll never forget the guy Hemophilia Association just looked him dead in the eye and he said, everything they say goes for us, too. And it was just, YES. And I've always had really deep respect for the Hemophilia Association ever since then because they stood up with us and said, we are fine, upstanding, employed people who have a chronic illness. And we are here with these people, and we have common cause.

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And that was – and, what happened was that we initially said that we wanted the insurance commissioner to just deny the red herring, just do not allow Empire to do this, and that we wanted to just call the legislature to step up to the plate and do something. And then we started thinking about it, and we started thinking about the fact that, that’s kind of dangerous because you just never know when you tell the legislature do something, whether they’ll do something that will, in fact, end up being worse than what you had initially started with. And so, what we decided to do was start meeting with Empire, and start seriously talking to them about what actually is going on, what is really happening. And – so, then they start telling us about – oh, it’s the commercial companies, and they’re picking our best customers away from us. So, we went and had a meeting with the commercial companies, the other companies. We met with the trade association, for the health insurance association of America. We also met with a number of the commercial other insurers – with Chubb, with Aetna, whatever and sat and discussed things with them. This was like – for them, this was radical, to be sitting and actually talking to people who are representing – who aren’t even, necessarily your insureds, who are saying, so, why do you do this? And, why is insurance structure this way? And, why are you doing this thing? What are the – and we were, actually, doing little negotiating things about – well, would you be okay with this, this and this? And, what about this, this and this? And what about if we did this? And, as we’re doing this, it was just at the beginning of the Clinton healthcare discussions. And, I don’t know if you remember, but the insurance industry stand on the Clinton health plan was, all we need is some small market reforms, and then there won’t any problem – just a few, small market reforms.

And, so, we were meeting with the legislature, meeting with the insurance companies. We were meeting with Blue Cross. And, what we decided was that, we wanted to sit down and make a list of what is our druthers. If we could have anything we wanted, in terms of health insurance, what would it be? So, we actually had a meeting, where we said, okay, what's our dream health insurance, and we wrote this all down. And it wasn't just ACT UP. It was the coalition of the groups. So, we decided that what we wanted was – we wanted that individual people should be able to buy health insurance, regardless of their health status. We wanted that it wasn't a possibility for them to raise the price of your health insurance if you used it – that, that shouldn't be allowed. We also were concerned about small business owners, because one of the things that we made clear from the hearings was that small business owners a lot of times, wanted to have health insurance for their employees, but the costs were so extreme in relation to – when you compare the cost coverage for two people, versus the cost for having coverage for 300 people, because the insurance company would give you a break, if you had 300 or 350 employees. But, they wouldn't give you that break, if you had two or three or five. So, we wanted to also have something about small business owners and helping to make health insurance equitable for small business owners, as well.

And, we sort of wrote this all up, as a series of principles, and started getting groups to endorse it. And, started going up to the legislature and actually lobbying them and explaining to them, who we were and why we wanted this. And the first time I ever went up to Albany and tried to lobby around stuff, they thought we were shills for Empire. And, the legislature just couldn't wrap around their brain around – no, we're the people that have the coverage. We're the people with the illnesses. They couldn't

understand that. What they could understand was, I'm here representing Empire Blue Cross and Blue Shield. Or, I'm here representing Chubb, or I'm here representing Aetna. But, the whole idea that we were representing the people with the problem – they couldn't understand this. And so, we started talking about saying that we were the basketball. There was a basketball game on, and the ball is now talking to you, because we were the ones that were being bounced from thing to thing to thing.

**SS: Who were some of the people that you met with?**

KT: Oh, well, we sat down and we started talking to the lobbyist for Gay Men's Health Crisis, because Gay Men's Health Crisis was one of the founding organizations of NYFAHC and they had –

**SS: And NYFAHC is?**

KT: New Yorkers for Accessible Health Coverage.

**SS: Okay.**

KT: See, when you're in New York, everything starts out with NY – New Yorker, whatever.

**SS: Who was the GHMC lobbyist?**

KT: Bob Jaffe.

**SS: Okay.**

01:05:00 KT: And, Bob Jaffe, at that point, was working for a lobbying firm called Malkin and Ross and they have a contract – they still have a contract with Gay Men's Health Crisis. And so, he started – he sat down and explained to us about the legislature. And, so, I'm going to give you my version of Bob Jaffe's explanation of how legislature works.

The first thing to understand is that the legislature is like high school. It's actually a lot like grade school, okay. And there are some people that got offended at somebody else – at something that they said or they didn't have lunch with them, or whatever – 30 years ago. And, they just keep that grudge. And then, no matter what – if person A is voted for it, then person B – no matter what it is, is going to vote against it, okay. So, one of the things that lobbyist are – lobbyists are like the kid in high school who wrote down notes on who it was who doesn't like so and so, and who it was who, whatever. So, they're the ones who know – if you want to get to this one, then you have to go to this one, because he's the best friend of this one. So, that was a lot of the things. The other thing was that – at least – I don't know if it's still this way, but, when we were working on the Empire piece, the senate was controlled by the Republicans, and the Assembly was controlled by the Democrats. So, what that meant was that you had to have a Democratic Assembly sponsor to introduce whatever legislation, or it was sunk. And you had to have a Republican Senate sponsor to introduce it, or it was sunk. So, we had to figure out a Republican senator that we could get on board to do this – to introduce the legislation that we wanted to do. So, we started going around and meeting with Republican senators, which primarily meant senators from Long Island, senators from Queens. Frank Padavan, at that point, was, I believe, the whip for the Senate and he was – Frank Padavan was a real piece of work.

There were – I forget who – we had to get the head of the Health Committee. We met with the Health Committee, we met with the Senate Insurance Committee. The Senate Insurance Committee was Guy Vellela. Guy Vellela had an elephant collection that was quite amazing. So, it was, come on in, have a cigar, see my elephant collection.

And, it was just wild to me, because what I know from the legislature. And here I am, up in the legislature, going around. And you had to – you had to learn to – that it was – Malcolm X says that you want to go for your goal by any means necessary, and a lot of people think about that as by any means necessary means with guns. Malcolm was very clear about his word choice, okay. And, if you ever read any of Malcolm X's stuff – he read the dictionary, so he would read things and ponder the choice of words. So, he meant, by any means necessary. That means, if the person that you need to get to, to sponsor your legislation is sitting there, talking to you, with a giant dessert plate button that says, I'm With the Pope, and I Vote – then, that's what you do. You sit and you talk with that person. If we had to go to meetings with people who were – they had big pictures of dead fetuses on their walls and things like that. I mean –

**SS: Well, how did these people respond to ACT UP?**

KT: Well, the thing was, that –

**SS: Let me ask you, also, this – were they ever surprised that you were ACT UP? Did they have a meeting with ACT UP and then you walk in. Did that surprise them?**

KT: Well, we didn't go up as just ACT UP. We went up as NYFAHC.

**SS: Okay, okay.**

KT: So, we were always very clear to have somebody from an AIDS group, somebody from a Multiple Sclerosis group – so, we would pick which diseases. And, if we knew that somebody in their family had a particular disease, we would move heaven and earth to get that person from that disease association in the room, with the legislator.

**SS: Would you say that the coalition was a front group? Was it controlled by ACT UP?**

01:10:00 KT: No. It was – it was a coalition of really equal partners. And, they also taught us a lot of things about meeting with the legislature and working in coalition. And, I'll never forget, the first time we met with Frank Padavan – I had actually gone up on an AIDS Lobby Day – because there's something called AIDS Lobby Day that's organized by the New York AIDS coalition. And you go up and you lobby on AIDS related things. And you go and you visit all these different legislators. And I had gone up to lobby with particular – to lobby on the health insurance stuff. But, again, with AIDS organizations. And, when you go up to legislators, you want to get the staffer who's working on your issue, okay. If it's an issue that the legislature really doesn't want to deal with, then what you get is, rather than getting the legislator – the staff who is working on your issue – because they all get assigned different bills in different areas that they're experts in. Rather than getting to talk with that staffer, you get to talk to the temporary assistant's secretary for the guy who actually knows much more about slot machines. So, you have to sit there and try to educate this person, and try to grill into them the things that you want to say. It's much harder.

When we went up with the coalition members, we got to actually meet with Frank Padavan, which had never happened to me before. I had never actually met a senator. And he sat down, and he was really focused on the fact that he was sitting in a room with AIDS people. That was – that was blowing him away. And he said – the first things out of his mouth were, first of all, I really resent having even breathed air with you people. Well, I was kind of, sort of not surprised, because I had read up a little bit on Frank's take

on a lot of things. But, we were sitting there with one of the women who was key in the Multiple Sclerosis Society. The Multiple Sclerosis Society is a very, kind of prim and proper, Upper East Side kind of a place. It's a very – there's a lot of Junior League members who are part of it. And, it's a very socially acceptable organization of volunteer time for. And she had never, in her life, been talked to in that that way. And she just – oh, it was wonderful, because, the thing is – if you really – don't ever get those women pissed off at you, because then she was – not only was she rock solid on our issues, she went off and got a whole bunch of people organized to try and get Frank out of office the next time. And it was – it was really fun to actually have these other groups be in room and kind of experience this. You also – it was a very different experience going to AIDS Lobby Day – where everybody's an AIDS organization, and being able to walk into the room with the Hemophilia Association and Brooks Brothers everything, and the Multiple Sclerosis Society and Junior League everything, and us. It was a very different experience.

**SS: So, what happened with the coalition, ultimately?**

KT: The coalition? Well, basically, we got our legislation through. We got – and it became the Open Enrollment Community Rating Law of 1992. In the last month of the fight to get it passed, the insurance industry brought in a million dollars of lobbying talent.

And one of the things that made the difference in that particular fight was that we went out and made – oh my God, I still dream about this – we made little brochures out of a regular piece of paper, and we got a folding machine, an ancient folding machine, from one of the City Councilman – he lent it to us, okay. It was, actually, Tom Duane's

office lent us this folding machine. And, it would jam, if you did more than four pieces at a time. And, we literally did cases and cases of paper. What we did is, we did a little – there's a little tri-fold folder that said, Empire's rates are going up, are you going to lose your health insurance?

And on, the inside, we'd done action steps. Call your legislator. And we did a different – we looked up the actual legislators for specific districts. And so, we did a different tri-fold for each district, and we went out weekend after weekend after weekend to the malls on Long Island, because we had to get those Long Island Republican senators. We had to build a fire and get them to understand why it was important to pay attention to this. And so, we would go out – it would be these little flying squads. I would go to the floor of ACT UP. I need two or three people to come out this weekend on a Saturday. We're going to – we'll provide the car, we'll get you out there. And, we're just going leaflet the mall. Okay. And people – these poor, innocent people would sign on and say, sure, I'll come. And then, I would appear with a case a paper, okay. All folded in these little tri-fold things and I would give them to them and they were, okay, we're not going home until we get this case going. So, we would just go from mall to mall and Michael Swirsky was wonderful – he knew where all the malls were. What do I know from Long Island malls? He was, like, oh, the Greenwood mall? Oh, it's a great mall – and we would go in, and we would just do these flying squads in to the mall. And the thing was, that sooner or later, mall security would figure out we were there and then, throw us out of the building, okay. So, then what would do is leaflet all the cars, okay. So, we're running around the parking lot, but the thing was, when you would go up to people and explain it to them, people were galvanized about this. They would make little

01:15:00



lines to get your flyer. And, I knew that we were going to win, because the day that we walked into a very – it was a very, very, very ritzy, North Shore Long Island mall. I mean, this place was – they didn't have any plastic anything. They had teak everything. And, I went into a men's store – I was, okay – at this point, I was just – every single vote. I just want – I was like a heat seeking missile. I was, like – a vote. You're a vote, you walking, here, have a leaflet.

And, I got myself totally geared – because, I don't come from money. That's not my background. And, sometimes it was hard to get the nerve up, to walk into these places that were just, like, can we help you? And, I walked into this incredibly wealthy men's store. It was – I'm certain that I never earned enough money to buy a belt in there. And I walked in – teak everywhere – and I walk up to the manager and I explain the situation to him, and he got it, immediately. Not only that, he was, like, give me all you have. So, I gave him 50 flyers. He got all the staff to come around and he said, we're going to lose our health insurance on this job, if these rates go up. We can't afford it. Here, I want you all to take a flyer, and I want you to all take one home to your family, and I want you to all call. And, it was, like, oh, yeah.

And that was – and, what happened was, that, on the weekend – we would go out on the weekend. We would call Bob Jaffe and tell him, this is where we're going. And then, the next Monday, he would wait until about noon or so, and then he would call in to say – call into that legislator's office and say, so, did I tell you? And, the phones would light up. And, that's the thing – is that, in terms of health insurance, people get it. It's very real for people.

**SS: Okay, so let me just clarify the facts about this piece of legislation.**

**The name of the piece of legislation was?**

KT: The Open Enrollment and Community Rating Bill of 1992. It's now the Open Enrollment and Community Rating Law of 1992.

**SS: And who was the sponsor?**

KT: To my eternal shame, I don't know. I don't remember now. Republican senator, Upper East Side.

**SS: Roy Goodman?**

KT: Yes! He was our official senate sponsor.

**SS: And when it was passed, what was the consequence? The concrete consequence?**

KT: The concrete consequence was really funny, because – remember this is during the Clinton healthcare reform thing. So, all the insurance industry flacks are saying, just a few market forms, that's all we need. We don't need single payer health insurance. So, that's what we did, basically. We wrote – they would always say, oh, open enrollment. Open enrollment means, anytime you want to go out and buy health insurance, if you've got the money, you can go, you can buy it, okay. And they can't refuse you, well or sick.

Community rating means that the price for your health insurance – the premium – doesn't go up, because you went to the doctor. It's based on the community experience of your community. So, all the people that have your health insurance, over a large geographic area, that's all the cost of providing health insurance to all of them is what sets the rate not the cost for you and what you did last year. So, those were the two

pieces, the two major pieces of legislation. We also got credit for pre-existing conditions. We were – a lot of people were concerned, when they would switch jobs, they would face a pre-existing initial waiting period, which meant, it was a certain number of months, that you had to pay premiums, but you didn't have any coverage for anything related to your particular illness.

01:20:00 And, every time you switched jobs, or every time you stayed on the same job, and they switched insurance companies with the new policy – even though you'd been working there for five years, 10 years, whatever – when they switched to a different insurance company, then you had a new pre-existing initial waiting period that you had to get through, with the legislation, it said, in New York. The longest that a pre-existing initial waiting period could be is 12 months. And, you get credit on any new coverage, for the number of months you've recovered on the old. So, if you worked two years for someplace, you had 24 months of credit. Even if the new coverage comes in with a 12-month, pre-existing initial waiting period, you get 24 months of credit. You start with full coverage, for the first day. And, you keep that credit, even if you have a lapse in coverage of up to 63 days. So, you can get laid off, and you've got two months to find a new policy or get hired somewhere new, and still not face a pre-existing initial waiting period. It was really landmark legislation, when it was passed.

And, I would be remiss, if I didn't give credit where credit is due. There's a man named Mark Scherzer, and he is a fantastic advocate for people with AIDS and with cancer. He is a private attorney, and what he does is, he takes on insurance cases for – on behalf of people with AIDS or cancer or other chronic illnesses who are suing their insurance companies. And he was, really – he was a consulting attorney with Gay Men's

Health Crisis, and he was instrumental in helping us – in helping to draft a legislation and helping us to understand some of the more technical pieces of New York State laws, etc., etc.

**SS: We're going to switch tapes.**

KT: I told you I could talk for a long time.

**SS: That's good. This great shit, man.**

**SS: Some of the people that you've mentioned – David Peterson and Bob Jaffe – are they still alive?**

KT: David Peterson is not, no. David Peterson died of AIDS – I want to say, in 1995. Yeah, I think it was in 1995, yeah.

**SS: So, you were spending an awful lot of time on this, how much time a week, would you say you were spending on ACT UP?**

KT: Well, in the midst of the open enrollment community rating thing, it was – I literally took about a month off work and just worked full time on it. It was – well, I mean, Monday nights were the main meetings so that's a whole evening gone. So, that's three or four hours. And then, the Insurance Committee meeting was generally Thursday night – so that's another night gone. And then, we usually had projects that we were working on. So, there might be several hours on another evening.

**SS: Because many people that we're talking to describe ACT UP as a way of life.**

KT: Yeah, oh yeah.

**SS: And, it takes over your life.**

KT: Yeah.

**SS: So, what happened to the rest of your life? What about your old friends – the ones who are not involved in ACT UP? Did you lose touch with them?**

KT: Well, see, I came – it was kind of a cusp in my life, because I was just – I finished graduate school, and then, of the friends that I had in graduate school – actually, a number of them were people with AIDS. So, some of them actually came to ACT UP or were in ACT UP with me. And, they've all now died.

But – graduate school for me was not – it wasn't an entirely a positive experience. So, there weren't a lot of people there that I really wanted to keep in touch with, when I was in graduate school, after I got out.

**SS: Because the time that you're talking about – the early 90s – there was a very high death rate in ACT UP. It was very constant. And so, when you people were working on these projects, did you discuss that, as it was happening?**

KT: We didn't – did we discuss that people are dying?

**SS: How many people you knew were sick and dying and the constancy of it.**

KT: It wasn't – it was like being – it was – that was our world. It wasn't – I mean, it's strange to think about it now, because now people aren't dying like that, so you can see there's a difference. But, at the time, it was, if you want to be in the lives of these people, this is what you have to – this is part of it. It's not something you can opt out of. I don't know if you saw the play *Jeffrey* – but it was all about, I don't like the fact that people are dying, I don't want to be with people who are dying, and if you're HIV-positive, I don't want to know you. And, if you're in ACT UP, that's, by definition, you are with people with HIV and people with AIDS. And what that means is, is that you're

01:25:00 – and for me, it was a conscious decision, because I'm a straight woman. I'm not infected with HIV. I don't come from the gay world. There's a whole other piece to my life that doesn't involve that. And it felt a lot like we're all in this trench together, and there's a war on. I talked to a lot of – I talked – because in my work life, I was completely closeted, as being in ACT UP. That was – if they had known at Phoenix House that I worked, was in ACT UP, I would have been fired.

**SS: Why is that?**

KT: Because ACT UP was doing needle exchange, at that point. And, Phoenix House is drug treatment. And, within drug treatment, to this day, there are many, many people who believe solidly that doing needle exchange, or giving people free needles, is fostering the chaos, is encouraging drug use. And, that's starting to change some now. I mean, the State Department of Health has taken a firm stand on harm reduction is the way that we are going. We endorse harm reduction, we teach harm reduction – that is what the State Department of Health has said will be the focus of HIV work, in a state with a huge amount of infection among IV drug users. That doesn't mean that drug treatment professionals are not conflicted about it and do not oppose it. They do. And, I was very concerned about that. And, I was very careful about keeping separate my work life and my ACT UP life and not telling people at work that that's where I it was. Or, that I was involved at all.

But, it was also – and when I was at work, I was working in in-patient or rehabilitation and there were HIV-positive people there. And, my job was to take people through pre- and post-test counseling and give them their results. And, it was – in a weird kind of a way, it was almost seamless. And, I – one of the things that was really

important to me in being in ACT UP was to have a place to take my rage, and to have a place – to know that there was a place that was going to hold people accountable, because I saw things, as a professional – I saw things, as a person providing HIV-related care, that were enraging and that within – and I didn't work only at Phoenix House, and then, left there and started training drug treatment professionals. And it was really clear that there were people that were getting sub-standard care. There were people that were not being treated well at all, etc., etc. There were people who lost their coverage and then got left out of treatment. I was seeing stuff like that. I knew people that were in that situation. And, I went – I firmly believe that being in ACT UP in those years was one of the things that enabled me to stay working, as an active professional within the HIV field – that if I hadn't had somewhere to take my rage and my anger, that I would have just turned them inward and just gotten depressed and unable to function and had to have left the field, burnt out.

**SS: Did you ever get personally involved with people in ACT UP who had insurance needs? Like a friend of yours who had an insurance need and would come to you and then your involvement would be emotional, as well as –**

KT: Well, yeah, I still had my brother with Marfan Syndrome. And, that was one of the things that really fueled me. I mean, yes, I did have that happen. Friends would come to me. Though my closest friends, I, literally, did insurance counseling with them. I sat and read their policies and explained things to them. But my brother, still was living in New York, was going to school at Cornell, and didn't know what was going to happen, in terms of his health insurance. And, I thought that the opening enrollment

community rating law was an incredibly personal one for me, not only because of my friends with HIV, but because of my brother with Marfan Syndrome.

01:30:00 And there was a moment when – because when you’re a professional in a field, they’re your professional colleagues and you kind of all hang out with them, whatever, whatever. Well, in terms of the legislature, the lobbyists and the legislators and all those folks – they’re all professional colleagues. I mean, yes, officially, they oppose each other or they whatever, but the lobbyist who’s the guy who talks for Empire Blue Cross and Blue Shield and who fights against the things that the commercial insurance companies want – they all go out to lunch together, and they all know everybody at the insurance department and they all – at one level, they – on off hours, they kind of pal around and this, that and the other, because, again, you’re spending all your same time talking to the same people and hanging out year after year after year up in Albany. And, there was one point at which the legislator for – the lobbyist for – Empire – who, I mean – I don’t even remember his name. It was this big, flashing lobbying company, and they had lots of big corporate clients and Empire was not even the least of the companies that he had. And he was – he just thought this whole thing was just a royal joke. He just totally didn’t get it at all. And, he said to me one time, you have no idea what you’re up against. He said that to me. And, I looked him dead in the eye and I said, and you don’t realize what you’re up against. And he said, you’re taking this so personally. And I said, yes, I am, it’s a very personal fight. And, he just couldn’t get over the fact that I wasn’t going to pal around and whatever, whatever. And I couldn’t get over the fact that this was central. This was really core. I wanted that law just so badly. And, I guess that’s – on one level, why I’ll probably never be a professional lobbyist, because, as a professional lobbyist,



you take your wins and your losses and I just went whole hog. I mean, I was working 16- and 17-hour days for that law to get passed. And a lot of other people were, too. It's not like I was all by myself up there in Albany. There were lobbyists that were helping us. There were the other people and the other coalition members – they were helping. They were going up to Albany and testifying. People were doing a lot of stuff.

And the thing was that when I was in ACT UP, people did die. And that, then, fueled at one level, the urgency of – this is real, this is not make believe, this is not play. This is – people really do die of this disease, and people really do die without treatment, and people really do die in the hallway of the hospital because the hospital wouldn't give them a bed. And, that's – I saw all of that.

And, I remember, distinctly, the summer of 1993. Was it '93 or '94? It was either '93 or '94 – I remember – that was the summer that all those people died. There was a period, there was a six-week stretch where somebody that I knew from ACT UP died every 10 days – every 10 days to two weeks. In that six-week stretch, I forget – I think I lost – I think four or five people died. That was when we had the funeral in Tompkins Square Park, was that summer.

**SS: For Jon Greenberg.**

KT: Yeah, yeah. I talked to Jon Greenberg about a week before he died, and I called – we were talking on the phone, and I was talking to him about coverage for alternative treatments, that I felt that I hadn't done enough. And he was telling me about, that he felt that he'd burnt out his liver using Glycyrrhizin – that he had put too much in and it had fried his liver.

**SS: What's Glycyrrhizin?**

01:35:00 KT: Glycyrrhizin is a licorice root extract that was being used – I think he used it intravenously. And – but we had this whole – I’ve had so many conversations with people in the last week or two of their lives, where they’ve been – it’s like when somebody’s dying, they get to a point where – yes, their body hurts, yes, they’re sometimes in unbearable pain, but it’s – and, what else is new? There’s a certain point, where someone just goes into – it’s almost like another dimension of, just, everyday above ground is a good one. Yes, I’m sick, yes, I’m ill, yes, I’ve got terminal cancer or AIDS or whatever, and I’m alive, and isn’t that wonderful? And, that’s the state that he was in, that Jon was in. He was living his life. He knew that he was very close to the end, but, it’s like – at a certain point, when you’re in a – a lot of people come to this knowledge of all the concrete pieces of somebody dying, when they’re 80. One of the things that I said was that, when you’re in ACT UP, when you’re working in AIDS, and when you have many friends who are HIV-positive and many friends who have AIDS, you learn a lot of stuff that’s not necessarily age appropriate.

You learn how to be with somebody who’s dying. You learn how to advocate, in the hospital, to get somebody a blanket when they need a blanket. You learn how to pack to go to the hospital. You learn to take the Lysol with you, because they probably didn’t clean the phone very well. It’s like all these little concrete skills that you pick up that people who are 70 or 80 – they have that because all their cohort is dying. There was a period of time when my social life was structured on which funerals I was going to, that particular month.

**SS: Is there a particular funeral that stands out for you from that time?**

KT: Oh, there are several. I'm not certain I can remember people's names, it's sad to say. I mean, Jon's was quite amazing. When we took his body and went up to the park and then had a funeral in the park – and kids are playing on the swing sets over here and somebody's lighting memorial candles over here. And there's this open casket, lying in Tompkins Square Park. It was – for so many of those years, it was – I felt sometimes surreal, in terms of – there's this war going on and I'm losing friends and people are dying here, and nobody is noticing. And, I felt that a funeral in the park was very much a – somebody died here today. Pay attention, people. This is real. This is what's happening. This is a concrete reality of what's happening in that house, in that house, in that house – this is happening right here. When I look at the AIDS statistics – and I don't know how closely you felt this – when there were 633,000 people with AIDS in the country – I can remember when everybody was really shocked that we'd gotten to 100,000 people with AIDS.

**SS: How many people have died of AIDS in this country, do you know.**

KT: I don't know. I stopped keeping track. There was a period of time when I – the first thing I read in the *New York Times* every morning was the obituaries – to find out who had died. There are many people, who's – the first notice that I'd had that they died was reading their obituary.

**SS: So, let's go back to actions.**

KT: I'm thinking of – David Feinberg wrote an article about going to memorials and – I don't remember the title of the essay, but it was hysterical, because when you've been to a certain number of memorials, it's – the testimony from the last lover, and the last, last lover. No, I'm the last lover. And all those things and the people

cruising at the memorial service, because that's – and people say, oh, it's so hysterical, I mean, it's horrible, it's terrible, it's nasty, the people cruising a memorial services, but isn't that the essence of life, to affirm your living in the midst of death.

**SS: Do you remember David Feinberg from ACT UP?**

KT: Oh, absolutely, yeah, yeah.

**SS: Is there anything in particular that stands out for you?**

01:40:00 KT: There are so many things. So much of what David Feinberg wrote – I read it, I was hysterical. I hurt myself several times reading things that he wrote. David Feinberg had wonderful glasses. He also was – he was one of those people who had not been born beautiful, and he set out to be sexy. And, I always thought that was an amazing thing. I always thought David Feinberg gave people hope on so many different levels.

**SS: In what way?**

KT: Well, I mean, one thing was, not being born beautiful, being born kind of nebbish-y, and then becoming this hunk of glorious manhood, by the time he died. Also, that you could live your dream. His dream was to live by his writing, and for many years, he had another job to support himself and then his writing took off. And, it was – I remember him talking at one point – I don't remember whether I was sort of listening in on the conversation or whether it was something – one of the things he read, he wrote that I read, but his whole thing about, when do you decide to let go of the day job? When do you decide to just take that leap off into whatever?

As a New Yorker, one of the things that's difficult is living space, and he always talked about his apartment in Hell's Kitchenette – that he had this little apartment that

really wasn't what he wanted, but it was something he could afford and he could manage and the location was good and this, that and the other. And, I remember, when he got his dream apartment. I got invited to a party there, and I remember – I thought it looked like a fairly, normal, average, everyday apartment. It was much nicer than the one in Hell's Kitchenette – until you went to the bathroom. Did you ever go to David Feinberg's bathroom?

**SS: I went once. I was in his apartment once.**

KT: It was an amazing, tiled wonderland with a Jacuzzi and a this and a that. It was – I remember it as being like a three-room bathroom, somehow. It was just huge and expansive, and you could understand how you could have a whole different sex life, if you had this bathroom. Those are some of the things that I remember about David Feinberg.

**SS: Thank you. Let's get back to your list.**

KT: Okay. Oh – Day of Desperation.

**SS: Yes, very important, since we're in the middle of Gulf II, right now, as we speak.**

KT: Oh, yeah. Well, Day of Desperation – we wanted to do some very concrete things, because when you're talking about when you're doing advocacy around insurance, it's kind of vague. It's hard to make a picture, whereas, when you're doing advocacy around a drug, you've got a pill. This is a picture of the pill or this is a picture of the lesion or whatever. So, what we decided to do were a number of small actions through the day. There was a march early in the morning that was –

**SS: Can you say what it was all about – the big theory of Day of Desperation?**

KT: I don't remember what the big theory of Day of Desperation was? Was it, we're desperate, because nobody's paying attention?

**SS: It was the Gulf War.**

KT: Oh, okay, so tell me. Do you remember?

**SS: Well, it was money for AIDS, not for war.**

KT: Well, I remember that there was a march through downtown Manhattan. So, we pulled out the banner that said, Insurance Discrimination Kills People with AIDS. So, we were going to march with our banner. But, we decided that since we were going to be doing it in lower Manhattan – lower Manhattan is like – that's insurance company heartland. So, we decided that what we wanted to do was we wanted to take back a street. John Street in lower Manhattan, at that point was, main street insurance company, U.S.A. So, we had bumper stickers printed up the size and shape of a street sign that said, Insurance For People with AIDS Street. And we went out at 4:00 in the morning, and got up on ladders and replaced all the street signs that said John Street and we put bumper stickers that said Insurance for People with AIDS Street, the entire length of John Street, on the street signs.

Now, you have to understand, okay, this is the Insurance Committee. The Insurance Committee were – I mean, we had our share of hunks. There were a couple of really nice looking guys in the Insurance Committee, but by and large, we were like researcher kind of people. We were kind of geeky. So, we were trying to figure out – okay, how were we going to get up on the ladders and how high do the ladders need to

01:45:00 be. And, I have to confess, that I overslept that morning, so I wasn't there on John Street. But, I do know that David Peterson, who was – David Peterson was this little nebbish-y, 50-year-old guy with little round glasses who looked exactly like what you would imagine an insurance company – not even executive – just like a middle-management guy would look like, okay. He's started climbing up on mailboxes, to get to the street signs, okay. And the police came by, and there's David Peterson, standing up on a mailbox, replacing the street sign with Insurance for People with AIDS Street. So, he managed to talk the police out of arresting him. So, the police, were like, just get lost, get out of here. So, they went off and had a cup of coffee and they went back to finishing up the rest of the street. I woke up, I got down – I met them when they were marching along with their banner, okay. We did our march with the banner, okay. Then, we went off and had breakfast. And then, we went off to Metropolitan Insurance Company, because they had – they hadn't done anything really extraordinarily bad against people with AIDS, but they had a very distinctive building – the Met Life building. And so, what we decided to do is, we decided to sticker the Met Life building with stickers – and I think I have them right over here. Do I have them? Aw, shoot. I'm sorry, we're going to have to cut for a minute, while I find my stickers. [KT gets up to look for stickers.]

**SS: That's okay.**

KT: Now – well, I'm going to have to describe it, I'm afraid. I'm sorry.

**SS: Okay.**

KT: I saved them for this historic moment. If I haven't worn you out by the end of this, if we ever get another time, I'll pull them out for that. But, the sticker said,

This Insurance Company Under Surveillance by the AIDS Coalition to Unleash Power.  
Health Care is a Right.

Well, I have to tell you something, we had these stickers – we had them made up, printed up professionally. David Peterson, who was a stickler for grammar and grammatically correct English – he had been delegated to go off to the printer and hand in the design. We'd had endless meetings about designing this sticker, and what the words would be and how many words and what would they say. And, David decided, on the way to the printer that rather than saying, Health Care is a Right, that he would say, Health Care Ought to be a Right.

**SS: That's so faggy.**

KT: So, we get the stickers back – because, of course, we were planning ahead, because we were worried about them. We get the stickers back and they say, Health Care Ought to be a Right. And, there was a catfight the likes of which you can't even imagine. It was, what do you mean it ought to be a right? Health Care is a right! No, no, no it's not.

See, here's the Bill of Rights, and these are the things that are rights and that is not one of the things in the Rights. So, it was like this whole – and that was one of the dichotomies, because within the Insurance Committee, we had people who were health insurance industry professionals who weren't really on board with the whole idea of a single payer healthcare like England or Canada or any other developed country. They were, let's do some market reforms. And, a little while ago you asked, what happened when the law got passed? The Open Enrollment Community Rating Law? That law put in place in New York State those “small” market reforms that the insurance industry,



nationally, was saying, we just need to do this small list of little market reforms, and then there won't be a problem.

01:50:00 So, it was great. Here's our experiment. In New York States, we're going to put in place those market reforms. We put those market place reforms in place, and we said, if you were going to sell insurance to the public in New York State, your insurance has to conform to these things. You have to take all comers, regardless of well or sick. You can't charge the sick people more money, okay. And, you have to give them credit against the amount of time that they had coverage on their previous job, with their previous coverage, against any pre-existing conditional waiting period. And that the longest that pre-existing conditioned waiting period can be, is 12 months. And that's true for individual buyers of health insurance, and for small businesses up to 50. And, the next day, when it became effective, nearly all the insurance companies left the state and stopped selling insurance. And our thing was, yo, Clinton people, this is what's going to happen. But, that's what happened. Now, there are a number of insurance companies that stayed – a smaller number. But, what's happened is, because they had to conform to the market and everyone was, oh my God, New York will go bankrupt – this, that and the other. Well, you know what? It's been 10 years – it's been 11 years now – 1992, 2003, and you know what? It works just fine.

**SS: How much longer did you stay in ACT UP after that?**

KT: I stayed in ACT UP until, basically, right around 1999.

**SS: Really.**

KT: Yeah, yeah. And the reason that I left ACT UP was that, by that time, basically it was Mark Hannay and I were kind of the insurance committee at that point.

There were a few people that were still left. And ACT UP – the membership – the people that went to ACT UP had gotten very small. It was, generally 50 people, 30 people, 60 people — somewhere around there. Now, what had previously worked was, we would go out and research an issue. We would figure out how to do the demo. We would put together the fact sheets, figure out whatever graphics, put out a press release, and we'd go to the floor and explain to them what it was, and then they would all come to our demo, okay. The problem was that, when you have a floor of only 50 people – what happens is that, if that's your strategy – even if you get a fifth of the floor, you've only got 10 people. And, more and more people were basically burning out, because it was, you could do all this stuff, and then there would be one other person that would show up for your demo.

**SS: Why do you think the membership got so small?**

KT: Because Clinton got elected, and a lot of the reforms that we needed and a lot of the drugs that we needed were available. People weren't dying at the same level, and people in positions of power were not so blatantly ignoring us. And, now it became – there was less of a pressure. There was less of a feeling that nobody's listening to us. If we don't do it, nobody will. And so, more and more people started to believe that the world is a good place and a safe place, and you don't need to really be watching what elected officials are doing, and what CEO's are doing – that, they'll do the right thing. And, I had always said that I wanted to be in ACT UP because ACT UP was a place that would hold people accountable, and that we would be able to do things and make change. And, that, basically that, I could change things through ACT UP that I couldn't change other ways. And what started to happen was that because I had been working in AIDS,

solidly now, at this point, for 10 years, I knew a lot of people both in my ACT UP life and in my professional HIV life to the point where, if there was something going on, that had to do with healthcare or health insurance that wasn't really working, I could pick up the phone and call somebody and say, listen, I just want to lay two or three things that maybe you need to check out – whatever, whatever. And so, at one level, I had acquired a certain amount of that power and I didn't – and again, it's the whole idea of, you don't – the goal of being in ACT UP for me was not to go out on a demo every single week. The goal was to accomplish change, and to do it with involving the least amount of effort possible. So, if you can do it without – by having a meeting with somebody or two or three meetings, or getting a petition together or going up to Albany and lobbying, then do that, rather than focus on getting everybody out in the street.

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And so, what happened was that more and more, the things that I wanted to work on were not things that the floor of ACT UP necessarily could support me in doing. And, the reality is, when it's a much smaller group, you really have to help on everybody else's actions, too. And so, what happened was that Mark Hannay and I were two of the people – we weren't the only ones, but we were two of the solid core people who could sit down with someone and write the press release for them and then help show them how to fax it out, help to get things going. And, it became more and more – almost every night, with ACT UP. And, I needed to have some more space, and I needed to have a life. So, that was – and the thing was, I could accomplish things outside of ACT UP that I wanted to do and I wanted to make change around. And so, that's why I stopped going.

**SS: You told me earlier that now you're involved in civil war reenactment and that that's something you're spending – you're enjoying, you're spending a lot**

**of time on. Is that, because you wanted to be in a community and when you left ACT UP – was it the loss of community? You decided you wanted to be in another community?**

KT: No, it was because I wanted a non-AIDS related hobby that – in every part of my life, because HIV is so central to who I am as a person, both professionally and then, through ACT UP, in my spare time. And then – also, many of my friends are living with the virus – that it started to feel like there wasn't anyplace that I could go that wasn't HIV-related. One of the things that's really important to me is church. And, I felt guilty for a lot of years that I didn't want to get involved in my church's HIV outreach or telling my church about some of the stuff –

**SS: What church are you in?**

KT: I'm a member of Calvary Episcopal. And the Episcopal Church has taken an early – took an early important leadership role, in terms of HIV. They did a whole campaign about our church has AIDS. But, I needed a place where I could go and grieve. I needed a place where I could go and not be the helper, not be the provider. Just go and be. And, I decided, after awhile, that I wanted more than just church, where I wasn't necessarily the one giving all the time. And so, I wanted a non-AIDS related hobby. And so, I became a civil war re-enactor.

**SS: There you go. So, I only have one more question, is there anything else on your list that you think we need to cover?**

KT: Oh, let's see. There was one action that we did. It was several years after the open enrollment community rating law got passed, and we developed a fairly good working relationship with the leadership of Empire Blue Cross and Blue Shield. And,

there was a rate hearing that they were asking for at one point, that was really extraordinary. And, we went to the legislature and we said, if this is allowed to go through, it's really going to be problematic. It's just extraordinary, and people are going to be very upset. And, they decided to let it go through. And, the decision was made. We went up and we actually had this, kind of, lightning lobbying campaign, right at the end of the year. It was late December – right going into New Year's. And, I remember they announced that they were going to still allow them to go for it, and we went on television and gave interviews on December 31<sup>st</sup> of that year. And then, there was going to be – because of the New Year's recess and all – and the weekend. It was New Year's was on a Friday that year, and so there were going to be four days. On the Monday, we were down at Penn Station, leafleting people, telling them what this is going to mean for them, because, again, the people that come through Penn Station are people that live on Long Island, and that was who we had to get through. And, I'll never forget – because the ACT UP workspace was on 29<sup>th</sup> Street, and Penn Station is at 34<sup>th</sup> and Seventh Avenue, and we had spent the weekend Xeroxing leaflets. And, we loaded two cases of leaflets on a little luggage carrier cart, and dragged it down the street to Penn Station, and sat up on the sidewalk, and people were coming out of Penn Station. If you've ever been to Penn Station in rush hour, it's like this river of people coming at you. And they lined up for leaflets. I'll never forget it. Because it had been carried on the news, through the weekend, and then, we were standing there, right at the exit to Penn Station saying, here's what you do to send the word up to Albany. Here's what you do, here's where you call.

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I've never had people have that kind of a reaction to a leaflet before. And, it always went back to me – I always held on to the knowledge that health insurance is real

for people, it's concrete, they get it, they understand. They may not be able to read or understand their policy, or know what benefits they have, but they know what it is to have the fear of not being able to pay for the treatment, to pay for the drug, to have it be economically out of their reach. And that's why I believe in my heart that we will have single payer in this country. It may take awhile, but it will come, because the way that we structure health insurance now is so expensive and so restrictive, that sooner or later, we will get enough people and reach critical mass. And, I don't think it's so far away – where people will realize that there has to be a better way.

**SS: I think we're over. I think that's a great way to end. Thank you, Karin. That was fabulous. That's just information that can't be had anywhere else, really crucial. Thank you so much.**

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