

Roundtable: Lenny Alberts, Jim Rann, Pasquale Natale and Irene Rabinowitz

December 2008

L: I'm Lenny Alberts, also known as Doctor Lenny Alberts also known as Doc Lenny. I moved to town in the summer of 1986. I moved here from Boston where I had been, amongst other things a one night a week volunteer at the Gay Health Collective at the Fenway Community Health Centers. So I've been involved from the very beginning of the HIV epidemic. Before it was HIV, when it was still GRID. I saw my first patient with GRID, he was a young man who was referred to me for surgery and in his routine pre-operative testing he had a very, very low platelet count for no reason, otherwise humanly healthy, and we figured that out and he was actually the first person seen at the Fenway and that was in 1981. Then I can remember we had no idea what was going on other than ...was it poppers? was it only in New York? was it only in Los Angeles? wasn't even sure that it was sexually transmitted at first and there was an awful lot of ignorance and an awful lot of panic. Someone would be hospitalized and they would be on reversed isolation precautions, the custodians wouldn't go in to empty their trash, the dietary would leave their trays outside the door of their room, nurses would refuse to go in and take care of patients and I was involved with one hospital at that time, what was then the Deaconess Hospital, where a few docs particularly Jerry Groupman, from the very beginning of things, started to be willing to see patients in a basement at night almost... so I was familiar with that when I came to Provincetown. Once I got here in 1986 I was recruited by a doc who I knew from Boston, Dr. Scott Luria, who was starting to see a few HIV patients. He left, he was replaced with a woman named Dr. Donna Cooper, who also started following HIV patients, but her heart wasn't really in it and I gradually became more involved in doing HIV care and was

involved in getting the first expanded access trials to Provincetown. There's a lot more to the story in terms of the politics, but... we'll all talk about that.

I: I came here in December of 1986, just 22 years, isn't that wild, and I moved here from New York and I lost my first friend to GRID as it was then 1982 and it was Peter Musgrove Newton and we didn't know what he had. He died of pneumonia and we didn't know why a thirty-two year old would just die of pneumonia. Before I moved here I worked at the Fortune Society which is an ex-offender organization and I worked there from '84 until the summer of '86 and that's when I started to work with people with AIDS and advocating the prison system of New York state to get condoms in there and some services for people when they came out of prison because they were just being discharged to the street. So I moved here.

P: I remember, because you and I were in the second training group for volunteers at the AIDS Support Group. That's when I met you, you were working and I remember meeting you.

I: Yup, and working for a non-profit that advocated for ex-offenders wasn't the most popular job in the world so when I moved here I signed up for the volunteer training that the then Provincetown AIDS Support Group was holding and I met Pasquale and Frankie Girolamo and eventually met you, met Lenny.

P: Well that first training there was and Phyllis Temple, Greg Russo, Lincoln Sharpless you were in the first training with Jackie Freitas, we were in the second with Ray Sullivan, Ed Gurry. She was facilitator, volunteer coordinator and eventually worked for the town nurses....Doreen,

Alice. The town nurse's office... it was a function of the town of Provincetown and then I was a volunteer from then, once we finished the training, then was hired at the AIDS Support Group in February of 1989 and I stayed employed there till 1995 as case manager and eventually trying to create housing for people with AIDS and I guess I left at the ground-breaking, that was my last thing.

J: Actually we were trained to be buddies, that was the buddy system that we had then.

I: To work one on one with people and sometimes it worked.

P: They used the Shanti Project as a model.

I: No wonder we were depressed

J: I saved that whole booklet. Catherine photographed it.

L: Everybody was dying; there wasn't much cheer in the world, for sure. And when word that there was care here and the support group and we were in the situation where people were getting thrown out of their homes, thrown out of their towns and the word got out on the street that this was a welcoming community to come to and people would come here, show up here sick, with no insurance, no housing, no friends, no family support, no prescription plan, not that there were any drugs in those days, no place to live and desperately ill and it seemed like every week another one would come into the clinic. In the face of pneumocystis or the face of

cryptococcal meningitis or horrible stuff.

I: Horrible, horrible stuff, which in retrospect and I think you and I may have talked about this, my first assignment as a volunteer was with a friend of yours (said to Jim Rann) and I was just sent there with someone who was dying and he was a little delusional and I didn't know what I was doing and if it wasn't for Jimmy and Barry Cook I would have been totally out there as a volunteer, although there was great work done by Alice and Doreen, the crisis, as you just described it was so immense, they way you just described it, that they we, the volunteers, just went out and did things. I remember that I had to sit there with him for four hours and I wasn't expecting someone who was that delusional and you and Barry Cook stopped by and said "How you doing?" and said "Don't let him run outside" which he actually did , but not on my watch.

J. Yeah, ten in the morning sitting outside of Ciro and Sal's on the bench there in his underwear, just smiling away, wondering what was going on.

L: Yeah, and it often wasn't pretty, people would be incontinent of feces, incontinent of urine, disoriented, febrile, coughing, covered with sores sometimes it was hard stuff for someone with medical training to deal with, never mind volunteers that hadn't had that hardening that you get in medical school and the fact that so many people were willing to step up to the plate and go in to these awful, awful circumstances, and yet be so totally giving was just one of the most amazing stories of the town really....and people did step up.

P: What I remember when I first became a volunteer and some of the things I used to do would

be to cook or to clean to sit with someone in their home, but most often the first thing I remembered when I walked in was the smell, there would always be a smell, like being in a hospital, or a nursing home in a way.

J: Yeah, then another thing we would have to do, he would be incontinent and we would have to shower him but we would have to stand with him in the shower because he was at that point where he'd be turning the hot water up, he didn't know hot water from cold and we were afraid he'd hurt himself that way. There were about forty of us all together that helped take care of Don.

I: It was an amazing experience to be thrown in there for the first time and then after that it just seemed we were all on auto-pilot, we couldn't cry.

L: You became numb but you knew what to do. Meanwhile, Keith Thurlow the plumber was going around to houses installing shower chairs for people, and hand held showers and doing that on his own time and Susan was involved, his wife, his then wife, Susan Stinson in the early days with Pentamidine, while the whole scandal of the dying. Well the first treatment Pneumocystis Pneumonia was killing people, usually within a few months of when they got it, and unfortunately, and I'll say this on the record, and it's still true that the nearest hospital, which I won't name but which happens to be in Hyannis was unable and unwilling to hospital any people and still, I think, has certain reluctance. So people had to be hospitalized they had to be transported to Boston. A lot of people would go into the hospital with Pneumocystis Pneumonia and never come out...go on the ventilator, get the comfort measures and they finally

discovered a treatment, an orphan drug called Pentamidine, which could be given by aerosol and there was a big hassle because it was an orphan drug. We were in a situation, Scott Penn, the then clinic administrator and I were looking to avenues to get this on the sly because if we were providing a medication that wasn't licensed, it jeopardized our clinic license. So we were doing it on the sly, in the back door for a few people but under the constraints that we couldn't let anyone know that we were doing it for fear. There was still a lot of political fervor. There were some people in Provincetown that were afraid that Outer Cape Health, which was then Health Associates, was being identified as the AIDS clinic and the mission was to serve all the community and people were starting to be afraid to go in there because they were afraid of getting infected. I remember throwing someone out, he wouldn't get blood drawn in the lab because he was afraid he was going to get AIDS from getting blood drawn in the lab. So there was a lot of education that needed to be done. But meanwhile everyone thought that we were unable to get Pentamidine and even though we couldn't admit that we were giving it so there was a guy in the clinic protesting the lack of Pentamidine, which really drove me crazy because we were doing it but we couldn't say anything.

J: But what happened through that was the state then saw and they did Ok it.

P: But prior to that the Coalition got its own machine and access to its own Pentamidine. The Provincetown PWA Coalition administered Pentamidine treatments to people outside of any medical..

L: There were bars groups you could go to, particularly in New York, where someone would

drive down to New York and get some of these supplies, get the Pentamidine and bring it back without a license because people were dying and how could you stand there and deal with legal technicalities while, people were dying. Pentamidine was the first treatment really that we had that had any chance of making people better, at least for a while.

I: And it was a comfort measure too...people were not understanding not only did it treat pneumocystis but it also made people..... the worst thing is not being able to breathe, anyone who has had asthma, pneumonia or COPD, any of that stuff knows that it's the worst thing, not to be able to, whether it cured it or not, to give people that comfort.

J: Then it became a preventative thing.

I: Everybody was on it.

L: And those were the days when we were just learning to do T-cells and just finding a lab that could do t-cells reliably and then once you started realizing that so many people had such far advanced disease, then anyone with low t-calls was getting Pentamidine. Then we gradually learned more about other ways of preventing pneumocystis, there were ways of determining who needed it, who didn't need it. We got a grant and we got a couple of carpenters, we built a special vented room in the clinic... Susan Stinson came out of retirement, gave up her knitting needles for a while and came back and was the Pentamidine nurse all day long, with people lined up for an hour long treatment for Pentamidine and I was the "doc", Matt Abar was there then, I think, a physician assistant who is still there and a few others. Tully was there for a while,

basically it was a team of me and Susan and it was getting so that we needed to have a mental health support group, because so many people were dying. I had a partner who died of AIDS and he wrote in one of his poems that in the early 1990's the town was averaging a funeral every two weeks.

I: And you know I was just thinking about Billy Furdon and he was hired a month after me at the AIDS Support Group sometimes us and the volunteers and Sandy (LaRoe) when she was there and Sam Demerest afterwards but sometimes the two or three or four employees at the AIDS support group and the volunteers were the only people in these peoples lives.

J: Right, because they knew....

I: The only people in these peoples lives and I think we all had to remember to keep that face on it. So when these things happen like the discussion about the Pentamidine. We're not just talking about FDA approval of a drug we're talking about something that effects individual people's lives, not only for treatment but for comfort and how can you deny that to someone.

L: There was a vast amount of anger and I think a lot of it was totally justifiable. We're talking about not may he rest in peace, Ronald Reagan, may he roast in hell for ignoring this both personally and on a federal government level for all those years of 1980-1988 when by his government turning its back on what was an emerging tragic epidemic, you can see what the difference in Australia, where the government was proactive in the early days and the United States where nothing was done and nothing was said. The FDA through up impediments rather than being proactive for treatment, that countless number of people died and he has that karma, hopefully haunting him forever. It was just... they were really tough days, you know and then George senior coming in after that, they were really just tough, tough times. Massachusetts, luckily, we're fortunate enough to live in a state that had the most generous entitlements, that you could sign up for programs, no questions asked, no residency requirement. You could be an illegal immigrant and you could still get services if you were HIV positive, from the state and God knows we bent through all sorts of hoops signing people up so people could get care.

I: You're right and it's like the Mass Department of Public Health had the AIDS Bureau so early that actually funded the AIDS Support Group at that time when other states didn't.

L: We still and I know the people who are still in the AIDS Bureau and I'm blocking his name right now because it's Saturday morning, I was just serving Thanksgiving dinner with him ... Kevin Cranston. Massachusetts still continues to have the best HIV Drug Assistance Plan (HDAP), they still make sure in this state that nobody falls through the cracks, although we're still facing in Massachusetts, as well as everywhere else, if anybody watches this live, that 25 %

of the people who are HIV positive in this country are undiagnosed, are not aware that they are HIV positive and it's the same old argument of going out and getting tested, counseling and testing still is an issue twenty-five years later.

I: It is and the lessons... We talk about what happened then sometimes it's still the shell shock, we were talking before we started to tape this, of people coming out of it, I don't know if you ever do. There are other analogies that you can make if you really want to compare one tragedy to another but Lenny talked about the grief counselor and I remember Leslie Patterson, who died of cancer, this is the worst irony, the grief counselor working with some of the consumers at the AIDS Support Group and the staff actually died of cancer. She worked with the staff and we didn't even talk. We were so shell-shocked we couldn't even talk and I remember Terry stopping me on the street, my friend Terry stopping me on Ryder Street and yelling, "So what, I still have AIDS and now the grief counselor dies." and we just broke up, we just broke up and we thought how more ironic could this be. We finally all said, "Yeah we need a grief counselor." None of us would talk to her, there was that thing that you couldn't, you were just there, you were just there in the moment.

J: Yeah, and at that time remember you were, all staff were required to go to it, we all went through post traumatic stress syndrome.

L: I would go back and I would find Susan Stinson and another person would come in and I would go like that and we would go out of the back porch and smoke cigarettes, and that was

about the only, just to take five minutes and vent, because you knew that you'd have to turn back in and there was another patient in the room and she'd have another patient there for Pentamidine and we'd give each other a hug and we just had to keep on going we just really...

J: One of the other things I remember about Outer Cape Health is, because in this day and age house calls weren't made, but you docs would come to people's houses and see them and it was kind of shocking because it wasn't something that happened anymore. Same with Irene, I remember you went to people's houses to sign them up as clients of the AIDS Support Group.

I: Yeah, if people could come out and needed services you needed to either go to where they were, whether it was a physical limitation or some kind of mental deficiency or because of fear. People didn't want to come in the building. Remember we first were negotiating for that building, you know where the office still is today. The Condo association originally said to Roslyn Garfield who was negotiating it, "We don't want signs in the window saying Provincetown AIDS Support Group" and Roslyn just packed up her stuff and said, "Ok my clients aren't interested and we have cash." I remember Rogers Baker said "And we have cash to pay for this." Nobody heard of that in 1988 and Roslyn just packed up her stuff and said, "OK, end of discussion, we'll look for something else." and they finally... and it was that thing, the sign and people being afraid to walk into the building.

P: You know I was just thinking of that and on the flip side of that, on the flip side of that too there came a period when the Consumer Advisory Board, the state mandated that every AIDS

organization in the state have a Consumer Advisory Board which consisted of consumers who worked with the agency to see that the things that they felt they needed happened and every once in a while, of course, a client would have a problem, whether it be with Outer Cape, the AIDS Support group, the drug store and, I remember, we would go to their home, a couple of us, sit down with them and write a letter about what their problem was and then try to mediate either between Outer Cape, it happened with Outer Cape several times and come to some conclusion and that was a great implement to have in place, that people could, even on the flip side, say, "Look I'm not getting this or I don't like the way that person talked to me at the front desk." It was great.

I: There was that thing, that maybe despite all the horrible stuff like Lenny described, like that stuff with Don in the shower, and how this replayed itself over and over again with all these people, there was this feeling that you could make changes, incremental things like that. Being able to help somebody, there was that feeling that there was some kind of change happening and every day, and I say this now, even in the job of helping out women, every day I learn from the people we serve, so for those of us who were working in it, we depended on the advise of the people who were living with this virus about how to, how to...

P: Who best knows what they need.

I: And there's lesson, it great a movement of....

J: Self-empowerment.

I: Yeah, self-empowerment, and for people like me who do the work to learn and to listen and to hear exactly what it is people are saying not what you think you want them to say.

J: And that's one of the good things about what happened here, the providers, Lenny specifically, listened to them.

L: It took me a while to learn to listen, and I'll admit that now. I came here with a surgical background and the doctor's God and the patients are somewhat less than God and for me to be able to listen and to mellow, you know that's a hard thing for a medical provider to do in a lot of situations and in that sense we all grew together. And I got to realize that the smarter my patients were and the more that they knew and the more information that they had the better off our therapeutic relationship was going to be, back and forth and I would have, certainly an awful lot of very sophisticated people, who were getting care in New York, getting care in California, reading things on line, I learned from my patients as much as, and the more that I had someone understand what we were trying to do the more likely they were for it to work but it took me a while to learn that.

P: I have to say because Lenny was my doctor for almost twenty years here in town, I tested positive in '85 when the test first came out because I needed to know but, you know, I was fine at that point, and as Lenny said he came here in '86 and I moved here full time in '86 and he became

my doctor and Lenny is the best possible doctor anywhere in the country anyone could have when living/dealing with HIV, I have to say that.

I: Yeah, it was a different time and I just think how people living with all kinds of illnesses now advocate for themselves, came from the work that you guys did. Everything here was cutting edge even though people look at San Francisco and other places. What was different here than the big cities is that it was so personal. It wasn't just that you were advocating for a faceless mob of people who were dealing with this, you were advocating for your friends and neighbors. You know, I don't know how we all did it all those years, I still think once in a while like how did we get through that?

L: It was a village here.

P: You know every once in a while what happens for me, it happened more back then and not so much now, when we were talking earlier about becoming numb when people die because it was every week or every other week, some people that you were very close to, friends that didn't even live in this town that died, and what happened for me was, you know, you would go through it, you would go to the service and then I would forget that they had died, I would forget that my friend so and so died and every once in a while when I remembered it would take my breath away. I would lose my breath and I would go, "Oh my God, he really is gone, he really is gone." It was amazing back then because it was too much, too close, too fast, for a human to absorb.

I: Yeah, the body armor went up.

L: Every year at the Labor Day auction, when on the front page of the auction would be the list of who had departed that year.

I: I hated that.

L: Someone died and you had no time to stop and process you still had a full appointment schedule and you had another set of people there and to stop once a year and to look at that list it was, "Oh my God", It was just.....

P: At one point Greg Russo decided for the Support Group to have printed and bound on parchment paper what he called the Great Book and it still exists, he actually had a case made for it - a beautiful wooden cabinet, and there are a pair of white gloves, if you opened this book you needed to wear the white gloves and it was in chronological order from the very beginning, each year, who died. You get to some of these years in the late eighties and early nineties and there were pages and pages of names and it was amazing.

I: It was. I actually grew to really dislike the book. Now in retrospect, I don't feel the numbness has gone away, but I think some of the members were made to protect ourselves, were made to survive. The one thing about human beings, it's our nature to survive and that made it sometimes, "why is it this person as opposed to that person?" Somebody who is 22 who didn't have any

chance of any kind of fulfillment in their life.

L: Some would come here and die within a few weeks and we didn't know how to reach their parents or if they had parents or you know we'd certainly have to spring to have them cremated and their ashes scattered. You wonder sometimes if there should be a monument like there was for the World War II Vets or for the Korean War vets

P. The Cultural Council has actually done something about it, I'm not on that any longer, but we did have \$15,000 to \$18,000 in place and we were going to put out a bid for artists to come with something that we could construct on town land. It hit some snags, we really don't have enough money at this point to do something outside, in this climate, something of any substance, but it's something that's on the books. One of the lighter things that I remember back then were memorial services became, you know, a regular, steady thing, and there were people, people who had lived here a number of years, who had the time, the energy, to think about how they wanted their memorial service to look and sound like and some of them were production numbers, with slide shows, choruses that came in from Boston. What's his name...

J: Stephen Clover..

I: He brought in the gospel show.

J: Paul Richard had the slide show and he made musical tapes of all of his favorite songs and how he wanted them played and the music was played though out..

P: And then you got a head sheet with his photograph and resume at the end..

J: The other thing about going to a memorial service you would sit at the memorial service and look around the room and see all the other people who weren't doing so well and wondering who was going to be next.

I: That was one of the hardest parts

J: There might be five to ten people in that room, or maybe more that you knew were already starting to have wasting problems or becoming very thin, Karposi and you began to wonder, you know, should I get close to this person, all that sort of emotional stuff would come up.

I: And that was part of it also, how do you start to become close to people, when you're in an intimate setting whether it's a physician and somebody you see out later at a play or something.

P: Especially in the town cause in this town if you're not going to live here two years you don't want to get to know them because they will probably just leave. Why should I have them as a friend, they're probably going to be gone. So there was the Provincetown factor and then there was the AIDS factor. How close?

L: The first ten years at Outer Cape Health people, old townies, would say I don't want to go see, I don't want you to be my doc because you're going to leave. After I was there seven or eight years they said, "Well maybe I'll start seeing you but we know that you're going to leave." then of course eventually they did.

I: That is the Provincetown thing, we're all cautious about new friendships, we're not snobs we're just cautious. I do think the good things that happened were the value and quality of the volunteers, people who just appeared to do whatever and I think about those volunteer meetings sometimes, extraordinary, there were people who were living with the virus.

P: We drove the van, we cooked dinners.

L: People also volunteered in town who weren't necessarily involved in the gay community, the locals who you wouldn't expect to see necessarily, who were there working just as hard.

J: Like cooking for their next door neighbor. Like guys who rented their next door cottage every summer who decided to move here and this person would make sure that they ate. Joyce Strong,

who passed away from pancreatic cancer a few years ago , she was right there. Terry Marheart's mother used to make quilts and pot holders and sell them at the auction and she lived in Worcester but she had this connection to Provincetown through her son.

P: And every once in a while at the Support Group ten or twelve acrylic yarn quilts, crocheted patchwork quilts would show up, gorgeous, beautiful quilts for clients.

I: Denise Joseph and that's how I met her, Provincetown born and bred ,she's a Helping Our Women volunteer. She still does it for Helping Our Women. And that how I met her, the pool table was still there and Denise walks in and says, "Hi, I make these, do you know people who would want them?" I've been friends with her since then, she just didn't even think about it, she just thought - people need these - people bringing them and making them for wheel chairs, I remember Rogers had one and I would take me out in the wheel chair and he had this little quilt that had pockets for whatever he was hiding in there, it could have been a substance that he maybe smoked that could have been, you know is now decriminalized in Massachusetts, but people would have things in the little pocket lap robes for people who had to use wheel chairs and it was just so thoughtful.

P: And then there were a number of people in town who were infected that no-one knew about. Those that chose not to come out, quite a few of those still. Walking through those doors of the Support Group where the sign was out front, for a lot of people, they couldn't do it. They couldn't walk in that place because of that sign.

L: Or come into Outer Cape Health for that matter. They would get their care out of town, hide their pills, if they were on pills.

I: What I do remember though is sitting in Napi's and it was when everybody was on AZT and had the little timers, the beepers going off. I remember sitting at Napi's for lunch once and it was like one o'clock and all these beepers went off, all these little pill box beepers to remind you to take your pills.

L: That was when AZT was about every four hours and I would radically say forget about the 2 A.M. dose, that is was worse for your health to take the 2 A.M. dose, the loss of sleep was worse and now it turns out that...

P: None of them should have been taken, none of the doses.

I: Is that true though Lenny?

L: We discovered that its half-life is long enough to use it twice a day. There are far many better drugs, but we were in the infancy.

P: It was the only thing we had.

L: Well when I was in medical school they told us that the average life span career span of a doc is thirty to forty years and fifty percent of what we are teaching you is going to turn out to be wrong, the problem is we don't know which fifty percent. So AZT was life saving for a little while but also made you worse, so once a better drug came along AZT disappeared. AZT bought some people some time, AZT caused some people a sooner demise. I can go back to 1987 when AZT first came out and knowing what I know now, would I have been so enthusiastic about prescribing it. I can remember going down the street and having people yell at me "killer" because I would try to talk someone into AZT and that I was a tool of the drug companies and that I was murdering patients by being an allopathic physician and trying to inject western medicine into something where people were desperately clinging to almost anything but.

J: We were looking for anything that helped and AZT helped, magic mushrooms, everybody does that, little green algae.

I: People overdosed on little green algae, they were out throwing up.

L: People were drinking urine, AL721, Peptide T.

J: I took that for five years and I think it saved me because it kept me off the AZT and the other treatments. I was in that trial.

P: I was one of the people who was on full dose AZT in the late eighties for several years, who had a beeper, who had to get up in the middle of the night, I kept taking it and I'm still here, but

not because of AZT I don't think, but I do remember people's reactions to my taking it....it was not encouraging, most people thought I was taking poison at the time and I needed to look at it as something good, that I was taking to live longer, so there was always a push/pull. It wasn't always encouraging here, some people definitely thought you were definitely doing the wrong thing, some thought if you had the needles of a certain kind of pine tree or reindeer antler or whatever.

L: A lot of people were going to Switzerland for those pine needles.

I: I kind of missed the pine needle story.

L: It was something in the Hemlock or Wintergreen, but there was a Swiss, a very expensive Swiss Spa the "cured" AIDS, and if you paid them three or four thousand dollars a week they'd be glad to house you and give you this installation of

I: The charlatans are there for every illness.

J: I think I remember somebody going to Switzerland and having their blood taken out and given new blood.

I: There was that thing too, if you do this blood exchange, will people be cured.?

J: And it didn't work.

P: To get back a little bit to the beginnings of our response, you were one of the early members of the Support Group and you were there at the beginning of the clinic. Were there anything back then that you could talk about that got it going, that were hindrances, anything at all in the beginning.

I: In the very beginning, Jimmy was more there, when I got involved I actually do think the hindrances were that we wanted to do something, we needed to do something and we really didn't know what we were doing and all those things were done in really good faith. And there may have been some mistakes done, we were taking care of people in ways that we really weren't equipped to, I just think that people were thrown into situations so quickly, and we didn't know and maybe in retrospect there would have been other ways to connect people to their families - to find ways. In some of the work I do now, people are separated from the families because of whatever, drug and alcohol issues or sexual orientation issues, whatever issues are separating them, but possibly we couldn't then for a good reason because people were dying so quickly and we wanted to give them some kind of emotional support...

P: and drug and alcohol abuse with HIV was a huge

I: And we didn't know what to do and I remember getting somebody in treatment and that was other thing was to get people into treatment....

J: And because they were HIV positive it was also an issue to get them in treatment.

I: The first time I called High Point and said "I'm a case worker at the Provincetown AIDS Support Group and I have somebody with severe alcoholism and I really think that this person is willing to go to Gosnold for five days and then go into a program for several weeks...we'll call you back about that admission. I said here's the name of the physician....it may have been you, I'm sure if you check with the physician they will, with our client's approval, share medical information, I never heard back. That was hard, I don't know what we could have done differently. I also think in retrospect, the things that we learned how to do, if we had reached out more and asked for more advice. We all looked at the Social Security Administration as in adversary, someone to fight with, I think there could have been another way we could have co-opted them. You know I do it really well now on behalf of our clients, these great people to work with and I understand now that when someone is disabled they really do want to help them. I think because we were so angry and so anxious to do something that we looked at anybody outside of our little world as an adversary and went in there sometimes with the gloves on.

P: We all were ready to fight.

L: I can remember fighting in Boston with the board of the Fenway, who didn't want the place to become a gay clinic. I can remember in the early days fighting with the board, some of the people on the board at Health Associates, who weren't quite certain that this was the direction that they wanted the clinic to go in and certainly Scott, Scott Penn and I fought that battle. Then it was

continually fighting with specialists, with other docs and you gradually work through the resources in Hyannis and realize that they weren't going to help you, that they weren't going to see your patients, and then even finding a panel, finding an HIV friendly neurologist in Boston, and finding an HIV friendly pulmonologist in Boston, it was just continually that I was hammering on these people saying "do me a favor." It was luckily because I knew a lot of people in Boston that I was able to get people in to get treated. I remember that somebody needed open heart surgery, needed a coronary artery bypass and no-one would deal with it, because they didn't want the risk of using heart/lung machine on someone who was HIV positive.

I: They're going to die anyway.

L: Yeah, they're going to die anyway, people didn't want to take that risk, or an orthopedist who wouldn't set a fracture because he was afraid he was going to break his gloves on the end of the bone, just endless, endless, endless battles with the medical system to get... you know, the number of times the ambulance would take someone to Cape Cod Hospital to assist us and have them diagnose them with prosoatitis and send them home because they didn't know what to look for, they didn't want to know what to look for. Educating the rescue squad not to bring people there, arranging ambulance transfers in Hyannis. The rescue squad could only go to Hyannis, to meet in a parking lot, to have another ambulance pick them up to get them to Boston. Finally getting Cape Air, once Cape Air got going and I could always call Cape Air to get someone to Boston and Cape Air would give up a seat but I needed to get someone to Boston fast and have a taxi arranged to meet them at Logan. It was amazing....

I: And that's why we were pissed off all the time...

L: Yeah we were pissed off all the time because you didn't have time to sugar coat things, you had another patient waiting in the waiting room with another cough, you didn't have time to do that.

P: God sent you there for us and you were a big help back then, with Boston and with some of those things, because some other doctors would have just done their thing and gone home.

I: And they did, they did.

P: I know.

I: Not to say that that isn't OK, to do your job and go home, but understand that it was a crisis, it was a new illness and people didn't know and people were dying that sometimes didn't need to die, that's the thing that still bugs you, were there different ways that the medical establishment could have but of course... There's still people with Lyme that are disabled and possibly dying because nobody is listening to them. So you see it happening with other illnesses periodically.

J: Well I think the power of the self-empowerment thing and the way that this town reacted has had a reflection going out from the town to other communities because they saw it work. One of

the things I was thinking when you asked about the hindrances, I remember that some of the business people didn't want some of the people visible who had AIDS, working or just in town. Fourth of July week-end you'd be walking down Commercial Street and would see people with canes or in wheel chairs who got out there and just said you gotta see this, this is what is going on, this AIDS and we've got to do something about it and it was brave for those people who normally wouldn't want anyone to see them looking all skinny or having Karposi and still they got out there and did it.

L: I can remember, say going to T-dance on a hot afternoon at the Boatslip and you'd see some people there in long sleeve shirts and long pants and then you knew why because they didn't want people to see their KS. You'd see someone dancing next to them in a tank top and short shorts with lesions all up and down the place and you'd know, being in your face, they were saying if you can't deal with this go **** yourself.

P: Greg Tice, who's back was covered with Karposi, from a distance it looked like a butterfly pattern, gorgeous in a way, and , he was conscious of that, he had it everywhere. But, was it the Fourth of July Parade or the Gay Parade, he'd take his shirt off.

J: He also did that on March in Washington and I remember taking him to Hyannis to the mall and that's where he would go in Filene's to the make-up counter and they would give him make-up and going to the mall with him, he would become more self-empowered about his mission. And we would sit there in the Food Court and eat lunch and he didn't wear the make-up and let

people look at him... very, very brave, he was so disfigured, but at the same time such a beautiful, beautiful guy.

I: There were so many people, so many people, I just remember Dave Wilse, the dancer and he lost his vision from CMV and he was walking around with a cane and he moved to Cambridge, and I called him one day and said "What did you do today?" and he said, "Went for a walk." and I thought, Oh my God the worst drivers in the world are in Boston or Cambridge, and you're out there visually impaired and he said, "Well I can kind of see out to the side a little." and I'm thinking, "he's going to get killed."

P: Maybe you can tell us about a couple of the women that we had as clients.

I: Liz Wolf, Oh my God, Liz Wolf. I'm actually still kind of in touch with her mom who lives in Los Angeles. Liz was our first female client and she was very funny and she also ended up being visually impaired and to have some serious neurological deficit, which caused confusion and anger, and it was interesting to have it with the work that I'm doing now with women, it was different back then for Billy and I, especially for Billy Furdon my then, office support husband, who still works for the AIDS support Group, you know, we wanted to do everything for her. We got her this apartment, thank you Pat Schultz and Lenore helped us and we got an apartment for her up a flight of stairs and she asked Billy for a spice rack and he said, "I'll get you whatever you want." and she was so funny, she said, "Let's make Billy nervous." and of course Billy went out and got her a spice rack, I think, with his own money actually. She really wanted this and we felt

like we wanted to do whatever we could for her, not make her feel like she was outside of the system, because it was really awkward for her to be in a system with all guys. She would absolutely join with the guys, she went to the Coalition, volunteered there for a while, beautiful red hair, she was a beautiful girl and very, very smart and it was, very, very tragic,

P: Then we had another, who was sort of in the closet for a while.

I: And I still feel, there was a young woman who died at the age of twenty-three and she was in an apartment across from the AIDS Support Group and actually my boundaries fell apart as case manager there and so did some of the VNA home health aids, we would just show up there, she would just know that she could call at three in the morning if she was scared. When I met her she was twenty-one and she died at twenty-three and that was one of the times that the lesson for me was learned. I can't go to my parents, I can't do this, they hate me, they think I'm a drug addict, and just to sit with her and her parents, and she ended up going home to Sandwich and dying at home with her parents, but she was an incredible young woman and had been training to be an EMT, was an artist and you know at twenty-three, if this had happened now there would have been treatments that would have prolonged her life, hopefully, it was hard to see that. It's always hard, whether it's someone forty or sixty, I just lost my mom, she was ninety-one, it's always hard, but to see a twenty-three year old be that sick and to constantly struggle to do things, so my boundaries went to crap on that really. She'd call me at three in the morning and I'd say, "OK, yeah, I'll come over."

P: Boundaries were all over the place.

L: Boundaries were all over the place, people knew my home number, people knew where I lived, people would show up on my doorstep sometimes, it happened more than a few times.....and going to the post office. I remember one of the things that saved my sanity was when the post office started delivering to my house. Because otherwise going to the post office every day at lunch to get my mail was, “Hey Doc, would you mind refilling this prescription, hey Doc, take a look at this.” I’d go to store that was still the A&P and someone would go, “Look at the ingredients on this, can I have this? Is this on my diet?”

I: Nobody in town had boundaries.

L: Yet that’s part of life in a small town. Your patient is your waiter or your postal clerk or your next door neighbor or your best friend or your... bridge partner.

I: Yeah.