Oral History # 072

An Interview With
Paul Gustafson, MD

Place of Interview: Houston, Texas
Interviewer: Lynn Schwartzenburg
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Date: 

The OH Project
Oral Histories of HIV/AIDS in Houston, Harris County, and Southeast Texas

To collect, preserve and make available the experiences of people impacted by the HIV/AIDS epidemic in Houston, Harris County, and Southeast Texas.
LYNN SCHWARTZENBURG: This is Lynn Schwartzenburg interviewing Paul Gustafson, MD, for The oH Project. The interview is taking place September 27, 2019, in Houston, Texas. I am interviewing Dr. Gustafson to document his recollections concerning the response to HIV/AIDS in Houston.

Good afternoon, and thank you for meeting with me.

PAUL GUSTAFSON: Thank you.

LYNN SCHWARTZENBURG: Let’s start at the beginning. When and where were you born?

PAUL GUSTAFSON: I was born on September 15, 1948, in New Bedford, Massachusetts.

LYNN SCHWARTZENBURG: Tell me about your parents.

PAUL GUSTAFSON: My father was a prison steward, and my mother was a housewife.

LYNN SCHWARTZENBURG: What were their names?

PAUL GUSTAFSON: Robert and Margaret.

LYNN SCHWARTZENBURG: Do you have any siblings?

PAUL GUSTAFSON: I do. I have three siblings: one brother and two sisters.

LYNN SCHWARTZENBURG: What’s the birth order? Where do you fit in?

PAUL GUSTAFSON: I was the second born.

LYNN SCHWARTZENBURG: The middle child. Tell me about grade school. What were you like?

PAUL GUSTAFSON: I was a good student, always. I got A’s and B’s pretty much right
from the beginning, and so I was thinking that I would be a scientist or something of that nature, but then I decided to go into the medical field.

SCHWARTZENBURG: So you liked math and science more than English and history?

GUSTAFSON: Oh, yes, definitely.

SCHWARTZENBURG: Did you play any sports?

GUSTAFSON: I played basketball and track. I was captain of the track team my senior year.

SCHWARTZENBURG: Is that in high school?

GUSTAFSON: Yes, that was in high school.

SCHWARTZENBURG: By then, you had moved, though, right?

GUSTAFSON: Right, we had moved in 1964, and high school in Taunton was 1964 to 1966.

SCHWARTZENBURG: Why did you move?

GUSTAFSON: My father — they found a better house is what happened.

SCHWARTZENBURG: Did you like the move?

GUSTAFSON: Oh, yes, I did. It was a smaller high school than New Bedford High School, and it was easier to acclimate to the smaller school, so I liked it a lot.

SCHWARTZENBURG: Did you always know that you’d go to college?

GUSTAFSON: Yes.

SCHWARTZENBURG: Where did you go to college?

GUSTAFSON: I went to college at Northeastern University from 1966 to 1971.

SCHWARTZENBURG: What was your major?

GUSTAFSON: Psychology. It was more neurophysiology than straight psychology. It was more of a scientific approach to psychology.
SCHWARTZENBURG: Did you graduate with a psychology degree, then?

GUSTAFSON: Yes, I did.

SCHWARTZENBURG: Then what did you do after college?

GUSTAFSON: After college, from 1973 to 1977, I was in medical school at the University of Vermont.

SCHWARTZENBURG: Why did you go to the University of Vermont?

GUSTAFSON: It was my first choice, and I got in, so I was very happy about that, and I had a good experience in medical school.

SCHWARTZENBURG: Was it because of your grade average, or was it because of the entrance exam, or —

GUSTAFSON: You’re talking about for where?

SCHWARTZENBURG: For medical school.

GUSTAFSON: Medical school, MCAT [Medical College Admission Test].

SCHWARTZENBURG: Yes.

GUSTAFSON: They still have that exam, but it’s much different now. I did well on the MCATs, so with my grades and the MCAT scores, I got in pretty easily, and it was a very good experience for me.

SCHWARTZENBURG: So you liked medical school?

GUSTAFSON: Yes.

SCHWARTZENBURG: Did you know immediately what you wanted to specialize in, or were you open-minded?

GUSTAFSON: I was pretty open-minded, but during my last year in medical school, my father developed lung cancer, and that kind of swayed me in the direction of cancer medicine. Then when I finished medical school, I applied for residency.
Medical school was 1973 to 1977. Residency was 1977 to 1980, and that was with the United States Public Health Service Hospital. Then from 1980 to 1982, I was a fellow in oncology at the National Cancer Institute.

SCHWARTZENBURG: What do you remember about medical school and your residency? What was that like?

GUSTAFSON: I remembered that there were a lot of patients that did well, but there were a lot of patients who didn’t, either, and who ended up on hospice. By and large, I think most of my patients did well and had a remission of one kind of another. That was actually before all of these fancy treatments that we have today where the chance of a remission is much higher than it was years ago.

SCHWARTZENBURG: Do you think there was more use of hospice back then than there is now, percentage-wise?

GUSTAFSON: I think now, there’s more percentage of hospice. That’s what it is now. The doctors are getting more enlightened about terminal care.

SCHWARTZENBURG: Hospice was fairly new then, back when you were in your residency, wasn’t it?

GUSTAFSON: Yes, it was new, but it was something that we were educated about. By and large, most of the doctors knew that when the terminal phase was at hand, that they didn’t need to be pushing chemo anymore or any other invasive therapy. That was an eye-opener for me to see that happen. When the patients went to hospice, I didn’t take care of them any longer. It was the hospice doctor.

SCHWARTZENBURG: I see. But you liked the hospice concept?

GUSTAFSON: I did.

SCHWARTZENBURG: Was your father ever on hospice?
GUSTAFSON: No. He had a very rapid decline. He had small-cell carcinoma of the lung, which is a treatable malignancy today. He actually had a good response to his chemotherapy, but then he developed jaundice. My mother and he were in Florida, and so they called me and said, “Daddy is turning yellow.”

I said, “Well, you’ve got to get back up here real quick.”

So they took a plane, and they flew up to Baltimore. Within two days, he was dead, so it was very rapid. He wasn’t sick long enough to really be in hospice. He came into the cancer center, and we diagnosed liver infiltration from a tumor. They actually tried to give him some chemo since he had a remission previously. I was okay with that, but after three days, it was clear that he was pursuing a terminal course.

SCHWARTZENBURG: When you were in public health, was it a residency?

GUSTAFSON: From 1977 to 1980, internship and residency. One year of internship and two years of residency.

SCHWARTZENBURG: What is that like? Is it a hospital practice or an outpatient clinic?

GUSTAFSON: It’s a hospital practice with an element of outpatient therapy. One afternoon a week, we would do outpatient treatment. We would see patients that we had seen in the hospital and follow up.

SCHWARTZENBURG: Was this oncology at the time, or what were some of the diseases?

GUSTAFSON: No, it wasn’t. It was a wide spectrum of illnesses ranging from infectious diseases to malignancies to diabetes to congestive heart failure. There was a wide spectrum of things that you would see in the hospital and then as an
outpatient.

SCHWARTZENBURG: Did you like public health, or you knew you wanted to get into oncology?

GUSTAFSON: Well, that’s a story. When I was in medical school, I joined something called the National Health Service Corps, and it was part of the USDHHS [United States Department of Health & Human Services]. What they told us was that if you matched into a Public Health Service hospital, that you didn’t have to pay back any time, so most of my medical school was free.

SCHWARTZENBURG: What a deal.

GUSTAFSON: It was quite a deal. But there was a fight involved there, because what they told us, and they told us in writing, that if we matched into a Public Health Service hospital, that we didn’t have to pay back any of the time that we had spent in medical school. The way it works today is that you do have to pay that time back. So if you do two years of training, then you would have to pay back two years on the other end.

SCHWARTZENBURG: You did an NIH [National Institutes of Health], correct, where you did your oncology?

GUSTAFSON: NCI [National Cancer Institute]. It was actually housed at the Baltimore Cancer Research Center, but it was part of the National Cancer Institute, so I didn’t have to go to Bethesda.

SCHWARTZENBURG: What was that like? Was that making rounds? Was it outpatient?

GUSTAFSON: It was both outpatient and inpatient. One day a week, we would do outpatient. Then the other days, we would do inpatient. I’ve often wondered
about it as to why we didn’t really pick up on the AIDS epidemic when I was in training from 1980 to 1982, because it was starting to be reported. The Centers for Disease Control had a monthly publication where they talked about gay men, men who have sex with men, were starting to show up with non-Hodgkin’s lymphoma and Kaposi’s sarcoma. I guess the non-Hodgkin’s lymphoma was treatable for a while, but the Kaposi’s sarcoma was really hard. You were lucky if you got a partial remission. Then once you’re past the partial remission, it’s time for hospice. I have often wondered why we didn’t see more of that. Maybe some of the patients that came in with non-Hodgkin’s lymphoma, maybe they had AIDS, but we were uneducated back then.

SCHWARTZENBURG: That’s interesting. So how did you get to Houston?

GUSTAFSON: Stephanie moved down here in 1981. We had, actually, a falling out, and she moved from Baltimore to Houston. I didn’t know where she was. Then I finally figured it out; that it was that she was living with her parents. As things worked out, we did really well together, and so we got married in 1983. That’s 36 years ago.

SCHWARTZENBURG: What did you do after you got to Houston?

GUSTAFSON: I went to work for the MacGregor Medical Association, which was the largest HMO [health maintenance organization] in the Houston area, bigger than Kelsey-Seybold. Kelsey was their major competitor. I had a good experience at MacGregor. I saw my first AIDS patient at MacGregor. By the time I left in 1986 to go to Park Plaza, I had a huge number of AIDS patients. I still saw general medical oncology, too, so that the patients with AIDS were in the waiting room with other oncology patients that didn’t have AIDS. By and large, they got
along okay. They really did, and there were some friendships that were sealed.

SCHWARTZENBURG: Was there any discrimination or problems for people with AIDS, or were they welcomed at MacGregor?

GUSTAFSON: Well, they were welcomed as long as I was there to take care of them. I can remember distinctly seeing the doctors walk the length of the hallway into my office, throwing the chart on the table, and saying, “Well, we’ve got another one here.”

I said, “What do you mean?”

He said, “Well, he’s gay and he’s got fever.”

I said, “Well, that could be AIDS. It could be HIV.” Of course, in that time, we didn’t know. We had no name for HIV. We didn’t have any.

SCHWARTZENBURG: Was there a screening test at that time?

GUSTAFSON: No, no.

SCHWARTZENBURG: So it was very early?

GUSTAFSON: Yes. So it was a clinical diagnosis where you saw certain things. Like I said, Kaposi’s sarcoma; non-Hodgkin’s lymphoma; Pneumocystis carinii pneumonia, PCP; advanced symptomatic hepatitis B. Cryptococcal meningitis was another one that patients would develop. They would develop central nervous system symptoms as in the meningitis. It would be common to see patients with weakness in a limb, weakness in an eye, in the mouth, inside of the mouth, and the other stuff that just doesn’t go along with the normal. So those patients had to be treated with amphotericin B, which is a very hard drug to take.

I don’t know if you know about amphotericin B.

SCHWARTZENBURG: Yes. I remember.
GUSTAFSON: We would get a remission, a partial remission with that.

SCHWARTZENBURG: Was that pretty much the only treatment available other than managing symptoms?

GUSTAFSON: There were some oral antifungals. Nizoral was one, but primarily it was amphotericin B. You would have to give that every two weeks or every four weeks. Patients would do okay for a while, have hope for a while.

SCHWARTZENBURG: This was seeing them on an outpatient basis. Did you have a lot of these patients that you saw as an inpatient, as well?

GUSTAFSON: Yes, mostly at Hermann Hospital.

SCHWARTZENBURG: At Hermann. Did they have a designated unit?

GUSTAFSON: At the time, they didn’t.

SCHWARTZENBURG: Were they on the oncology ward or floor?

GUSTAFSON: Yes, they were.

SCHWARTZENBURG: So Hermann was the primary hospital that you admitted to while you were at MacGregor?

GUSTAFSON: Yes. Simple stuff, diagnostic stuff like doing a thoracentesis or something like that, I would do that at Del Oro. If something was going to be just in and out, I would do it at Del Oro. If a patient had come in with systemic symptoms, it was clear that they were going to need a complete workup, so they would go to Hermann.

SCHWARTZENBURG: Were many in ICU [intensive care unit], or mostly on a regular floor?

GUSTAFSON: Early on, patients got treated aggressively, and so it wouldn’t be unusual for them to go to the ICU. With PCP, it was a common one to go to the ICU,
Pneumocystis carinii pneumonia. Those patients most of the time did okay, but then when they relapsed, it was clear that they weren’t going to do okay, based on experience. So we were of the mind back then that if somebody had relapsed PCP or relapsed any of the other infectious diseases, that they shouldn’t go to the ICU. Most of the patients were okay with that, and their partners were okay with that, too, because they knew that it was going to be gruesome there on out. So no, we didn’t use the ICU a lot. I can remember using it on a number of occasions. In those days, you had to wear gowns and gloves and all that because we weren’t sure what we were dealing with. That always makes it harder to care for a patient.

SCHWARTZENBURG: Because of that barrier?

GUSTAFSON: Yes.

SCHWARTZENBURG: Were there a lot of friends of your patients or families of your patients there at the hospital?

GUSTAFSON: Both, family and partners. The patients were classified as IV [intravenous] drug abusers, heterosexual, men who have sex with men, and transfusion-based cases. So the heterosexuals frequently would show up as women, and we did have a number of male heterosexual cases we weren’t able to classify. From the history, we weren’t able to figure out how it was transmitted. It didn’t matter, really. IV drug abusers were a different population than the men who have sex with men.

SCHWARTZENBURG: How so?

GUSTAFSON: They were really different. The men who have sex with men were young, educated. There were an equal number of — I don’t know equal number, but there were patients in the Caucasian category, African American, Hispanic. I
had patients from all those categories. Then the transfusion-related cases were sad because they got AIDS from blood that was tainted, and we didn’t have a test for HIV back then. We didn’t even know that it was HIV.

SCHWARTZENBURG: But you knew that it was from the transfusion?

GUSTAFSON: Oh, yes. I had two patients who were AIDS because of blood transfusion, and they were twins. They were hard to care for.

SCHWARTZENBURG: In what way was it hard?

GUSTAFSON: I think that they were distraught that they got AIDS from a treatment that they needed to have, so they were demanding, and I spent a lot of time with them. They both died.

SCHWARTZENBURG: Were they hemophiliacs?

GUSTAFSON: Yes. As far as treatment of the infections and everything, some patients with standard infectious diseases, and they would be treated with appropriate antibiotics. Chemotherapy for non-Hodgkin’s lymphoma was CHOP: Cytoxan, Adriamycin, vincristine, and prednisone. Then they added — I forget what the other one was. I mentioned the amphotericin B.

How long did the patients live? Full-blown AIDS, they probably lived 9 to 12 months. Then there would be another patient that would take that patient’s place. It was back and forth, back and forth. We had the whole ninth floor of Park Plaza Hospital. They dedicated it to HIV, three pods, maybe 25 to 30 patients per pod. That’s how significant it was.

SCHWARTZENBURG: That’s just the inpatient, plus everyone that you were seeing as an outpatient.

GUSTAFSON: Right.
SCHWARTZENBURG: That’s devastating.

GUSTAFSON: At MacGregor, the doctors were concerned about gay patients with certain symptoms, so they were primarily afraid of contracting the illness.

SCHWARTZENBURG: They felt it was more communicable if they had certain symptoms?

GUSTAFSON: Yes. I had given a talk on HIV/AIDS back before we even knew what it was called. The purpose of my talk was to help the doctors understand that they didn’t need to worry about contracting the illness.

SCHWARTZENBURG: How was that received?

GUSTAFSON: It was received okay, but they still continued to bring them down to my office every time there was a question, even though it might be just the fact that they’re gay. I remember seeing patients for the doctors, and I was the doctor in charge now. Once they brought them down to my office, I was in charge.

SCHWARTZENBURG: Do you think it was more than just HIV/AIDS? Was it because they were gay?

GUSTAFSON: I think that’s partially true, but I would work with the doctors on how to work up a patient. I would take them back to their office and say, “Here’s Mr. Smith. He has fevers, chills, sweats, and shortness of breath, so let’s send him downstairs for an X-ray, and I’ll be happy to look at the X-ray and see what I think.” Sure enough, they’d have pneumonia. Then transfer was complete.

SCHWARTZENBURG: “You looked at the X-ray; he’s your patient now.”

GUSTAFSON: Yes.

SCHWARTZENBURG: After MacGregor, where did you go? Why did you leave MacGregor, first?
GUSTAFSON: I left MacGregor in 1986 and stayed there [Park Plaza] until 2000. I just wanted to have a more enlightened approach to HIV. I was by myself at MacGregor. There was nobody else that was there to help me, and then I wasn’t really sure about the nursing care that they were getting.

SCHWARTZENBURG: Really? Why?

GUSTAFSON: Neglect.

SCHWARTZENBURG: Because of their HIV status of having AIDS?

GUSTAFSON: Yes. I knew that Park Plaza was an enlightened area, and I knew there were doctors there that I had knowledge of that I talked to a number of times, and actually I saw a couple of patients in consultation with one of the doctors. I could just tell that the nursing care was superior, the level of care was superior, and I didn’t have to worry about neglect, and so it was very easy for me to switch over to Park Plaza. I enjoyed my time there. I felt like I was on the frontline of some military operation.

SCHWARTZENBURG: Because of how efficient it was? Is that what you’re saying?

GUSTAFSON: No, because of the experience itself.

SCHWARTZENBURG: Cutting edge?

GUSTAFSON: Yes, but how difficult it was to actually take care of the patients in a simple way. I still kind of feel like that’s what was going on, was that I was part of a military approach to the care of patients.

SCHWARTZENBURG: Had treatment improved when you were at Park Plaza?

GUSTAFSON: Yes, AZT [azidothymidine] had been around for a little while, and we were getting some benefit from AZT. Then there were other, newer drugs. I mentioned Epivir as one of them. Following the AZT and Epivir treatment, there
were numerous drug cocktails, as they put it back in those days. I don’t remember those cocktails, to tell you the truth, but for me, it was the AZT and Epivir.

The cocktails were coming along after that, and so now HIV is a treatable disease. People can live for long periods of time without developing malignancy or infectious diseases.

SCHWARTZENBURG: How big was your practice when you were at Park Plaza?

GUSTAFSON: At any one time, probably 20 patients with HIV, and that equaled out to several hundred patients. I had a standing order sheet for HIV patients, which included cultures of blood, urine, stool, and spinal fluid if necessary, and a sputum culture, FB [fiberoptic bronchoscopy] for PCP. Frequently the patients who came in with breathlessness and shortness of breath needed to have — and then they would have infiltrates on the X-ray. So the diagnosis for those patients was PCP, so they would need to undergo a fiberoptic bronchoscopy, the biopsy, and a lavage. Those patients initially did well.

SCHWARTZENBURG: Would patients come in and out of Park Plaza, or were they too sick to be discharged?

GUSTAFSON: No, they could come in and out. Yes, they could come in and out.

SCHWARTZENBURG: For about a 9-, 10-, 12-month period after diagnosis?

GUSTAFSON: Yes. In order to induce a remission, it was frequently necessary to give steroids. Again, you’re giving steroids to somebody who is immunosuppressed already and wants to feel better. They frequently felt better for a number of months, but then it would relapse. Then you were left with hospice, again. Some of these patients, I would look after at home. I would go to their house. Friday
afternoon, I went to see patients in the home setting.

SCHWARTZENBURG: Not many doctors do that.

GUSTAFSON: No. Anyway, they weren’t able to go to the clinic or the hospital, so they were terminal care, pretty much.

SCHWARTZENBURG: Were they on hospice, or this was just part of your practice?

GUSTAFSON: At that time, it was not hospice. It was strictly Dr. G., and it worked out okay. They had access to me whenever they needed it. Their partners were generally pleased with the care that they got. I think they recognized that, “Here’s a doctor that comes to the house. We’re lucky.”

SCHWARTZENBURG: Right, they were. Were you on call, then, 24/7 [24 hours a day, seven days a week]?

GUSTAFSON: Yes.

SCHWARTZENBURG: Not sharing call with anyone?

GUSTAFSON: I was sharing call with Dr. Portnoy. I don’t know if you know him.

SCHWARTZENBURG: Yes.

GUSTAFSON: He’s an ID [infectious disease] guy. I’m not an ID guy, but I know enough to take care of his patients who didn’t have AIDS and had just regular infections. Dr. Portnoy was a good guy for me. In fact, Dr. Portnoy and Dr. Burnazian were rounding buddies of mine. I don’t know if you know Dr. Burnazian.

SCHWARTZENBURG: I don’t recall him.

GUSTAFSON: I don’t even know if he’s in practice anymore. Portnoy saw patients with HIV. I’m trying to remember. They [Legacy Community Health] made it possible for me to go home at night most of the time. But if I had a problem that
they weren’t going to be able to deal with, I would go in.

SCHWARTZENBURG: You were saying that they made it possible for you to go home at night because they could cover for you?

GUSTAFSON: Yes. Pretty much most of the time, they were able to do it.

SCHWARTZENBURG: Is there anything else? Anything I missed?

GUSTAFSON: We talked about the monthly review of medical literature, and so that was an important thing for everybody because we were able to share information from the literature.

SCHWARTZENBURG: That was at Park Plaza, right?

GUSTAFSON: Yes.

SCHWARTZENBURG: Was that a review of a case and a review of the literature, or just the literature?

GUSTAFSON: Both. We would discuss upfront what we were going to discuss so that we didn’t cover the same topic.

Another thing is that I published several letters to the editor from The New England Journal of Medicine and The Journal of the American Medical Association, both on HIV and the incidence of HIV at an HMO. That was widely circulated. I can’t remember what year it was, but the International AIDS Conference was held in Florence, Italy, so we got to go to Florence and present our paper. Then there was an article at the TMA’s [Texas Medical Association’s] annual meeting. It was on HIV and the incidence of HIV in Houston and in the HMO population. I can remember presenting that information, and then the next morning, in the San Antonio newspapers, in big, bold print, “AIDS increasing in severity and in numbers.” That was taken pretty much from my talk.
SCHWARTZENBURG: Were you ever at MD Anderson?

GUSTAFSON: No.

SCHWARTZENBURG: Tell me about CASA – A Special Hospital.

GUSTAFSON: CASA is a converted apartment complex. It’s very much a homey-type atmosphere that was converted to care for patients, general patients. It had oxygen in each room, and they were pretty much able to care for most patients. Now, I saw patients with oncology-related problems as well as HIV. The oncology patients were a wide spectrum of problems: breast, lung, pancreas. Those patients could go to CASA with insurance, and the insurance administrators were real happy about it because it was very much discounted. It was very low.

SCHWARTZENBURG: Compared to a hospital.

GUSTAFSON: Yes. So if somebody needed chemotherapy, I would go there and admit the patient and write the chemo orders, which might include five days of chemo, and then they would watch them for a day. Then we’d discharge them. Then we’d see them as an outpatient and wait until the next round of chemo, which would be like four weeks later. I learned a lot about oncology there because it was much more attuned to how I felt medicine should be. It was a great place to see patients.

Then other patients that we would see would be patients who were uninsured, who didn’t have any resources at all would come in, and patients with Medicaid would come in. There were patients that were seen at the Thomas Street Clinic for blood work and stuff like that, so I didn’t usually have to draw any blood on those patients. They would fax me the results. Whatever reason
why they were staying there, we would then be able to make a decision about
treatment. There was a certain amount that the Thomas Street Clinic would allow
for a patient at CASA. I know when we lost our Ryan White funding one year,
we were devastated, but we were able to get it back.

SCHWARTZENBURG: You were medical director at CASA; is that correct?

GUSTAFSON: Yes.

SCHWARTZENBURG: Do you remember for how long, or how did that happen?

GUSTAFSON: I’m not sure. I think it was four or five years maybe, something like
that.

SCHWARTZENBURG: Was it soon after they opened, or had they been opened awhile?

How did that happen?

GUSTAFSON: No, it was soon after they opened. I don’t know what Gretchen told you,
but I know it was — I think I was medical director for most of the time that they
were open.

SCHWARTZENBURG: Was that what you were doing full-time, or you had a practice,
too? Were you still at Park Plaza?

GUSTAFSON: Oh, yes, I was still at Park Plaza.

SCHWARTZENBURG: You were running around like a madman.

GUSTAFSON: Yes, but it was a good place, and I remember your mom. Does she
remember me?

SCHWARTZENBURG: Oh, yes. She said you were one of the good ones.

GUSTAFSON: That’s nice.

SCHWARTZENBURG: What else would you like to tell me about your experience with
HIV/AIDS in Houston?
GUSTAFSON: It taught me a lot about terminal care and how you can really help the patient and their loved ones by caring for them right up to their end. I later became — for a while, I was a hospice doctor, for a couple of years. I’m not sure what years I was a hospice doctor. I did outpatient hospice, which required visits, an initial visit and then a visit maybe once a week.

SCHWARTZENBURG: To a patient’s home?

GUSTAFSON: Right, the patient’s home. I think I was able to do that because of my experience with HIV/AIDS, to be compassionate, to be caring, to be loving, and to be with a family and the loved ones during that time. Again, HIV/AIDS put me on the right track.

SCHWARTZENBURG: You were practicing medicine during the most intense time frame of HIV/AIDS. That must have been very hard.

GUSTAFSON: Yes. I had burnout in 2000, and I sold my practice to Rios and Quesada, so they took over my patient responsibilities. From there on, I was in administration, administrative aspects of hospice, but they took all my patients, oncology patients as well as HIV/AIDS.

SCHWARTZENBURG: Do you know how many patients you had at that time?

GUSTAFSON: At that time, probably 50. They let me know when people were failing. I can remember one young lady. Her name was Lynn. She developed PCP for the second time, so she was admitted to Park Plaza under Rios. I went by to see her. It was pretty sad. That was around 2000. I wasn’t able to handle it anymore, so I retired. I’m not sure why I wasn’t able to deal with it when I did so well for so many years, but that’s the way it was.

I’m not sure how your interview with Dr. Gathe is going to go, but he was
right there on the frontline. I’m sure he’ll have some interesting comments.

Dr. Gathe was an infectious disease doctor. He took care of patients with AIDS. Interestingly enough, he didn’t refer that many patients to me. I’m not sure how he handled the lymphoma part of it, but from the other side, I referred patients to him.

Ed Stool, I think you mentioned him. He was the pulmonologist of choice because he knew exactly how to work up these patients for pneumonia, tuberculosis. Pretty much if he did a bronchoscopy and the result was PCP, we knew pretty well it was PCP. His contribution was immense. He died a couple of years ago. What they tell me was he died because he didn’t recognize the symptoms of chest pain he had been having for two years, and then it got worse, chest pain, so he died of MI [myocardial infarction] just like that [gesturing]. He was a funny guy.

SCHWARTZENBURG: He was.

GUSTAFSON: Did you interview him?

SCHWARTZENBURG: No. I think he died before we started this project. Can you tell me about the AIDS Interfaith Council?

GUSTAFSON: The AIDS Interfaith Council was an important part of the care of my patients with AIDS. Also, it changed names a couple of times. It changed to FIRM, Foundation for Interfaith Research and Ministry, and then CarePartners, which looks after Alzheimer’s patients. It started out with AIDS patients, though, and it was a congregation-based program. It was spiritual ministry for patients with AIDS. Then as time went by and treatment for HIV/AIDS became standard, the need for AIDS care teams no longer existed, and so CarePartners was formed
and now is a very important cog in the treatment of Alzheimer’s.

[END OF AUDIO PART 1]

SCHWARTZENBURG: How were you involved with them?

GUSTAFSON: I was on the board of AIDS Interfaith Council and FIRM.

SCHWARTZENBURG: You were saying that during the time of AIDS, they were providing care team support for people with AIDS?

GUSTAFSON: Yes. Meals, housekeeping, transportation.

SCHWARTZENBURG: Where would the volunteers come from?

GUSTAFSON: From different churches, mosques, and synagogues throughout the city. Back when FIRM was the name, they were still looking after HIV/AIDS patients, there were 40 or 50 churches, so it was well-subscribed.

SCHWARTZENBURG: How many clients were there, about?

GUSTAFSON: Maybe 100 at a time.

SCHWARTZENBURG: Significant, yes. Then how many people would be on a care team, about?

GUSTAFSON: Probably five to seven, that many.

SCHWARTZENBURG: That’s good.

GUSTAFSON: It was quite a program. It got a number of international awards and a presidential award.

SCHWARTZENBURG: I would imagine.

GUSTAFSON: Yes, it was really something. One of the patients that I cared for through AIDS Interfaith Council was — Michael Koepke was his name. He was the brother of Connie Nelson, once married to Willie Nelson, and she would come into the clinic, and we would talk about different things. We were looking after
her brother, and he died, but he was a patient of FIRM. So Connie Nelson was asked to be on the board, basically because of her brother.

While she was on the board, from the late 1980s through maybe 2005, maybe — I mean, a long time — she would bring in talent from the country and western genre. Willie Nelson came in, Johnny Cash, Kris Kristofferson, and Waylon Jennings.

SCHWARTZENBURG: These are for fundraising events?

GUSTAFSON: Yes. We were always impressed with how connected she was.

SCHWARTZENBURG: That’s a good addition to the board.

GUSTAFSON: But she stepped down from the board, so they don’t have that connection anymore. I can remember her brother, how devastated she was when her brother died.

SCHWARTZENBURG: I’m wondering what your thoughts are about sort of taking a left-hand or a right-hand turn, whichever way, from medical oncology into AIDS. Why did you do it?

GUSTAFSON: I did it because it was necessary. These patients frequently had malignancies. I mentioned the non-Hodgkin’s lymphoma and the Kaposi’s sarcoma. The lymphoma was a treatable disease for a while, but then it would relapse and be untreatable. Kaposi’s sarcoma, even though we treated it with standard chemotherapy according to the CDC, I never had a good response to the Kaposi’s sarcoma. In fact, we had some unbelievable cases. Two of them were physicians. One was a radiologist, and the other one was an administrative physician, both at MacGregor. Then I had a couple of other patients that had lymphoma. So it was an easy thing to bridge, to go from oncology to HIV
oncology.

SCHWARTZENBURG: But there were plenty of oncologists that just refused to see them?

GUSTAFSON: Right, right.

SCHWARTZENBURG: But you didn’t?

GUSTAFSON: No, that was fine for me. We were able to do it.

SCHWARTZENBURG: What do you feel your biggest contribution was to the care of HIV/AIDS patients?

GUSTAFSON: To the care of AIDS patients and their families, I felt that the families needed a lot of support and I was able to give them that support. That’s the big thing for me. I think that the patients and their families were happy with the care that I was giving them. We had patients come from all over to see me because they heard about me. They would have to find an apartment. Most of these patients were young and were educated, had good jobs, so money frequently wasn’t a problem. I feel like I did as much as I could. I did whatever was necessary. I did it for the patients and their families.

SCHWARTZENBURG: I thank you for your time and for sharing your stories with us. I appreciate it.

GUSTAFSON: Thank you.

[END OF AUDIO PART 2]

[INTERVIEW CONCLUDED]