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

Oral History # 047

An Interview With Gretchen V. Thorp

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AN INTERVIEW WITH GRETCHEN THORP

LYNN SCHWARTZENBURG: This is Lynn Schwartzenburg interviewing Gretchen Thorp for The oH Project. The interview is taking place October 23, 2018, in Bay Saint Louis, Mississippi. I am interviewing Ms. Thorp to document her recollections concerning the response to the HIV/AIDS epidemic in Houston.

Welcome. Thank you for doing this.

GRETCHEN THORP: Thank you for inviting me to participate.

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

GRETCHEN THORP: I was born in New Orleans, Louisiana, a long time ago, in 1947. I grew up there and went away to go to college, but all my growing-up years were in New Orleans.

LYNN SCHWARTZENBURG: Who were your parents?

GRETCHEN THORP: My parents were Anna Marie and Glenn Clasen. My father actually was in city politics in New Orleans. He was the councilman-at-large in New Orleans as well as their chief administrative officer for years. He was on city council during the integration and segregation trials and tribulations. That was an instrumental part of my growing-up years. He was very forceful in fighting for equal rights. With that, our family certainly took a lot of abuse over the years, but through that process, I watched my father and saw how important it is to stand up for your beliefs, even if that means having a lot of abuse during that time.

He got out of politics. He was in politics for about eight to 10 years. He got out of that, and then he was appointed by Lyndon Johnson to be the regional director of the Equal Employment Commission. So through the years, I watched my dad very involved in fighting for equal rights for individuals.

My mom was a teacher. She was a brilliant lady. She was a scholar. She taught Latin and the Classics in high school, and she loved every minute of it. She was a disciplinarian. She was the one who taught me that if you're going to do something, you're going to do it right and you're going to do it right the first time.

Both my mom and dad were very important figures in my life.

SCHWARTZENBURG: What was the abuse like? Some of the backlash?

THORP: By "abuse," it was verbal abuse. I remember phone calls, hateful phone calls. I remember cartoons of my dad when they were doing the political cartoons in the newspapers, and I remember some of those. I was pretty young at the time, but I can remember that vividly. I can remember that there were even members of my dad's family that were not thrilled by his stand, and so there were many times just in family conversations that he would have to listen to how he was mistaken in the work that he was doing.

SCHWARTZENBURG: What about friends? Their circle of friends?

THORP: Their circle of friends. One set, who were very important to me, they were like a second Mom and Dad. They would take me on vacation. I was best friends with their daughter. But they did not approve of what he was doing, so it was an interesting dilemma. We all still remain friends, which is great. I mean, this is what our world needs more of right now, is being able to have those differences of

opinions but still maintain friendships. There were definitely some friends that did not approve of the work that he was doing or his beliefs but were still there as friends.

SCHWARTZENBURG: You had some very important lessons very early in life, it sounds like.

THORP: Yes, they were good. They were good.

SCHWARTZENBURG: Do you have siblings?

THORP: I do. I have an older sister. She's three years older than I am. I always say that she's the brilliant one and I'm the one with the common sense. She was my older sister, and she went to a high school for gifted individuals. She went to Newcomb College and then to Tulane Law School. She was a trendsetter, because at the time, a female lawyer was not a common thing, so she was one of about three to five women in her class and would often be called the clerk as she walked into the courthouse. She went on to be an attorney and worked many years. She left New Orleans right after graduating and then went to the D.C. [District of Columbia] area and stayed in the D.C. area and primarily worked for the government.

SCHWARTZENBURG: What high school did you go to?

THORP: I went to Martin Behrman High School in New Orleans. I grew up on the West Bank of New Orleans. There was a section that was called Algiers. I went to the same high school that my parents went to. Many of my teachers were my parents' friends, and that always makes for interesting times.

SCHWARTZENBURG: You can't get away with anything.

THORP: No, not a thing. Growing up in Algiers was very similar to growing up in a

small town. We were in the big city, but we had the small-town atmosphere. We certainly had the close neighborhood, and everybody knew everyone. Particularly, again, with my dad being in politics, and then going to school with my parents' friends as my teachers and principals, made for a close little network.

SCHWARTZENBURG: Yes, sometimes too close. What were your interests during high school?

THORP: I was pretty active. I was with the in crowd. I did yearbook staff and National Honor Society and just all the clubs and activities of an active, involved high-schooler.

SCHWARTZENBURG: Where did you go to college?

THORP: I watched my sister stay at home and go to Newcomb and Tulane, and I decided that I needed to get out of town. I already knew that I wanted to go into nursing, and so I selected a school based on the nursing program they had to offer. I wanted to go to school out of town but not too far out of town, so I went to Texas Christian University in Fort Worth, Texas. I decided to get my bachelor of science degree at the same time that I was getting my nursing degree.

SCHWARTZENBURG: What year did you graduate?

THORP: I graduated in 1969.

SCHWARTZENBURG: That was early on when they were offering baccalaureates for nursing, wasn't it?

THORP: It was pretty early on. I mean, it had been around for a while, but probably the majority of people were still just going through a two-year program or a three-year program.

I'll tell you, on that note, though, I remember the nurses that had gone

through the two-year program that were coming back for their bachelor's programs, and I was always impressed, because they were so knowledgeable already about the skill side, and now they were really coming to learn the more in-depth information about disease and processes. I'm sure they learned a lot more than what we did as young people trying to learn everything at one time. That was impressive to watch.

SCHWARTZENBURG: Once you have the clinical knowledge and the experience of taking care of people, to come back and then learn the theory behind it, it does have more meaning.

THORP: It was amazing, and they appreciated it. I mean, we were going through the process, and this is what we needed to do to get our degree and to become the nurse that we wanted to be, but they really, really appreciated the knowledge that they had. I'm not recommending that as a way to do it. It's just an interesting take on it, and I'm sure they got a lot more out of it than what we did as young teenagers coming up to nursing school.

SCHWARTZENBURG: Where did you do your clinical?

THORP: At TCU, we went through the Harris Hospital System, which is now massive. It was not that big when we were there, but the Harris Hospital System in Fort Worth I understand is now just a massive system. We did clinical at Harris Hospital, Cook Hospital. There was a mental health hospital that we had relationships with, but Harris was the main place where we did our clinical.

SCHWARTZENBURG: Did you have a favorite interest within nursing?

THORP: You know what? At the time, I really, really didn't. One summer, I worked in surgery in New Orleans. I went back home, I went to New Orleans, and I was

working in surgery as a surgical tech, and I loved it. I just loved it. I was amazed. When you did surgery and you opened somebody up, what was inside looked just like the pictures in the book. It was just like, "Wow, they captured that."

I didn't want to be the circulating nurse because you didn't get to do anything. All you did was unpack equipment. I would often joke that what I really wanted to do was to work with one surgeon and be his scrub tech, and then I could make rounds and write all his orders and what have you. That never happened, and I never did really pursue it, but that was one of the thoughts as I was going through. I loved, I just loved my summer that I did as a scrub tech. I thought it was fascinating.

SCHWARTZENBURG: After you graduated, where did you work?

THORP: When I graduated, my roommate and I decided that we wanted to live in Houston. I particularly wanted to live in Houston because of the Medical Center. When you're a young nurse, wow, what better place to work than the Houston Medical Center? So I did, and I really don't know how or why I ended up applying, but I went to M.D. Anderson, and I applied as a pediatric nurse. My first year, I worked as a pediatric nurse at Anderson. Loved it, loved it, loved it. When I graduated, I was Florence Nightingale. I was ready to save the world, and particularly I was ready to save all those kids. We were going to take care of them, make them all better, and send them home.

It didn't happen. Quite an education. It was a huge culture shock because at the time, staffing was not at the levels that it should have been for the intensity of care that we were providing. We would at times have 20 IVs [intravenous]

going with little solusets. We didn't have all the machines that would beep and alert you.

SCHWARTZENBURG: You'd have to calculate drips per minute.

THORP: Calculate the drips per minute, and the little solusets would run dry. You'd get to one end of the hall, and by the time you'd get to it, the soluset was run dry. Huge education, huge learning curve, but a wonderful, wonderful, wonderful experience of taking care of people, families working together supporting one another. Amazing, just amazing.

SCHWARTZENBURG: So they formed a little community to support each other, the families?

THORP: Definitely. But again, this was way back, and so a lot of the rooms were semiprivate rooms. A lot of the rooms were wards. I remember, and I don't know how many, but I know one room in particular was a ward, and the moms would be sleeping on cots crammed all together, so they couldn't help but form a community, but it was a supportive community. When one mom had to leave for a little bit, the other mom was there. They'd work together. Then there were the patients who would support one another and support the nurses.

We would go in treading gently when little Tommy who had been down the hall had died and little Johnny would say, "Oh, that's okay. He's with the angels now." [Pauses, reflecting]

So, a huge learning experience. Early-on pediatric oncology did not have a lot of answers, and we lost a lot of kids. Florence Nightingale did not save all the kids.

SCHWARTZENBURG: That's a harsh reality.

THORP: The only reason I left was, I got married and I moved away, but I would have stayed. I would have stayed at M.D. Anderson, and that would have been interesting to see where that led.

SCHWARTZENBURG: What were relationships like between physicians and nurses at that time? Had it started transitioning from you give up your seat for a doctor when they walk into the station?

THORP: I think Anderson was maybe a little bit different. Actually, I know it was different, because later on when I was working at some of the neighborhood community hospitals, we were still getting up when the doctor walked in and gave the seat to the doctor, and, "Yes, sir," "No, sir," and, "What can I get for you?" At Anderson, we were dealing with a lot of students and interns and residents, and so we really were working together as a team.

SCHWARTZENBURG: A teaching hospital.

THORP: There was so much that was still unknown. There was so much that we were still struggling to do that everybody knew that we had to work together.

SCHWARTZENBURG: In many instances at M.D. Anderson, the patients are segmented by the type of cancer. But I imagine on the pediatric floor, you saw everything, right?

THORP: Everything, right. There was just one pediatric floor, and it was everything.

SCHWARTZENBURG: What an education.

THORP: The 16-year-old with head and neck cancer, I still remember her. She was gorgeous, and she just had this huge tumor. [Chokes up]

So we did, we saw a little bit of everything. And little bitty kids. Again, you get educated through college, and then you get educated.

SCHWARTZENBURG: Right, real world.

THORP: M.D. Anderson was a major part of my education when I got out of nursing school.

SCHWARTZENBURG: After you moved away, what did you do?

THORP: I did some general med-surg. At that time, Ron, my husband, was still in the military, and we were doing a little bit of moving around. I did a little bit of med-surg in the state of Washington, and then we got out of the military, and I was not nursing for a couple of years and had children.

We finally, finally, finally ended up back in Houston. At that point, I went to work part-time in our neighborhood hospital as a 3:00-to-11:00 supervisor doing supervisory nursing, and it was your typical neighborhood hospital, having a lot of the people that would come back routinely.

At that point in time, a lot of people were coming in and out of the hospital for testing. When they had their annual physical, they checked into the hospital for three to four days, and we did all the scans — no, probably not scans at that point in time. We were doing X-rays and barium enemas and what have you. So you saw a lot of the same patients coming back and forth. Again, that's where the doctors would have been the ones that you were standing up for. [Laughs]

SCHWARTZENBURG: That's right, and a whole different intensity level than M.D. Anderson.

THORP: A whole other intensity level, correct.

SCHWARTZENBURG: More concierge nursing.

THORP: Right, but we had our challenges.

SCHWARTZENBURG: Oh, yes.

THORP: But for the most part.

SCHWARTZENBURG: Because things go wonky on night shifts. That's where everything comes off the rails, in the middle of the night.

THORP: I worked 3:00 to 11:00, and it can get pretty wonky too because you don't have all the support staff there, and some strange things can happen. You never knew what was going to be coming into the emergency room. That was Sam Houston Hospital in Houston, in the Spring Branch section.

From there, I had a really interesting experience. I went to work, on a part-time basis, doing performance — what did we call them at the time? The name has changed through the course of the years, whether it was quality improvement or performance improvement, but I was at Thomas Care Center in Houston, which was a facility actually licensed as a nursing home. It had the skilled beds on the first floor, and on the second floor, it had a Level MR [mental retardation] 5. These were the children that were born profoundly retarded, totally handicapped. We probably had 100-plus kids on this floor. I was not doing nursing care. I was there to do performance improvement, and so I did not do the hands-on care, but was exposed to everything there. That too was an education. I mean, we're talking profoundly challenged children.

SCHWARTZENBURG: Were you doing improvement for accreditation purposes?

THORP: It wasn't for accreditation. I'm sure it was just for their licensure.

SCHWARTZENBURG: What kinds of things? What would that look like? Infection rates?

THORP: Just as far as the documentation, infection rates. For the children, even though

they were profoundly affected, they still had a regimen that had to be maintained as far as social skills, learning skills, and number of hours and time that they needed to be in those therapies, and so we were looking at all of that. Tracking weight was an important thing for children, as far as failure to thrive, and so a lot of attention was paid to the numbers related to their weight management and feeding, which feeding was always a challenge and all that went into that. It was sort of an oversight as far as physical care as well as skill level of care and documentation.

SCHWARTZENBURG: After that, what happened?

THORP: After that, and I'm trying to remember. I was working at Thomas Care Center with a woman, and I think she was the one that had initially been approached by someone to come work for this program that was just getting started, and that was CASA. Originally, originally, when CASA was started, it was going to be a pediatric facility. It was going to be a pediatric facility caring for children who had catastrophic or terminal illnesses. The concept was to be a homelike environment to provide the care and to provide hospice types of care but also full treatment if that's what the family desired. It was felt at the time that that was critical for children because so often parents are not ready to go into hospice care. They want to continue treatment as long as they can.

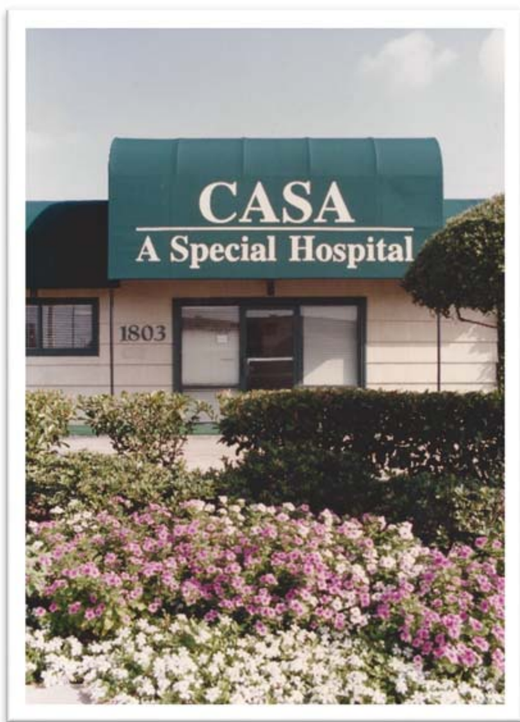
Anyway, backtrack to I was working with an individual, and I think she was the one that was being recruited. She was not interested in the position, and so she made the recommendation for myself and the other woman that I was working with at Thomas Care Center to be interviewed for the position at CASA.

From Thomas Care Center, I went to this program that was not even

started yet. It was a vision. It was a dream. Sandra Pierce and I were recruited. I was director of nurses. She was going to be the supervising nurse. We were recruited basically to set up all the policies, procedures, get all the guidelines that we were going to need to meet, and set everything into place to open up this new facility.

SCHWARTZENBURG: How long of a process was that?

THORP: It was a long process. It took us about a year. It took about a year because of the building and the licensing. It wouldn't have taken a year to develop policies and procedures, but it took a year to go through the licensing process, and the finish-out of the facility. It was a moving target to try to figure out what we were doing and what we were not going to be doing and the policies and procedures that would be involved.



CASA – A Special Hospital
Houston, TX. n.d.

SCHWARTZENBURG: Describe the facility of CASA.

THORP: I gave you a packet which gives pictures of the facility. One of the things that made it special was that we took an existing apartment complex, renovated it, and made it meet hospital codes, which was an amazing process. I don't know that I would recommend that anybody try to do that again, especially from an existing [facility]. To qualify, this was an old apartment complex that was renovated to meet hospital codes. The concept is wonderful. The concept worked. But if ever I were going to make a recommendation, it would be that you start from scratch and you build the apartment complex to meet hospital codes. Trying to

renovate and trying to make an old apartment meet those standards was tough and continued to be tough throughout the years that we were there.

SCHWARTZENBURG: What was challenging? The accessibility requirements or —

THORP: Oh, all of it, yeah. The accessibility, just general layout. We didn't have an inside corridor at all, and so to enter all the rooms, you were outside and you entered from the outside. On a rainy day in Houston, Texas, that made it very interesting for the nurses to carry their medications and to get —

SCHWARTZENBURG: Yeah, med carts, you can't really roll them down the hallway if it's pouring down rain.

THORP: That's right, right. It made for some challenges as far as that's concerned. We had constant problems as far as it being an old building with challenges such as leaks and plumbing issues.

SCHWARTZENBURG: How many units were there, about?

THORP: It was a 60-bed facility.

SCHWARTZENBURG: Was it single occupancy? Double?

THORP: We had some private rooms, and we had semiprivate rooms. The difference, which we took pride in, was for the semiprivate rooms, what made it a semiprivate was, it was a two-bedroom apartment. A patient still had the privacy of their own bedroom and then would just share the outer portions of the apartment. It wasn't like being in a semiprivate room in the hospital, where all you have is a curtain to pull between you. In this semiprivate room, each individual had the privacy of their own bedroom and then were just sharing the outer portions of the apartment, which worked beautifully.

SCHWARTZENBURG: You had to follow all of the — was it JCAHO [Joint

Commission on the Accreditation of Healthcare Organizations] at the time accrediting hospitals?

THORP: We did, and we didn't get JCAHO-accredited for a couple of years, but we were licensed by the Texas Department of Health, and our licensure was actually special hospital. That's how we were licensed. We were licensed as a special hospital. Yes, we had to meet all the licensing rules of a special hospital. Anything, I mean, as far as the fire regulations and sanitation, how we set up our pharmacy, how we delivered our medications, everything was based on hospital standards. I have to add, that when we did receive JCAHO Accreditation, it was with Commendation. We were very proud of that accomplishment.

SCHWARTZENBURG: So 60 beds, some of them are one-bedroom, some of them are two-bedroom. Do you have a call system for nurses?

THORP: We had a call system, yeah.

SCHWARTZENBURG: Just like in the hospital? Pull the button, and the light comes on?

THORP: Yes. The nurses just had a little bit farther to go.

SCHWARTZENBURG: Roller skates.

THORP: In the rain.

SCHWARTZENBURG: And stairs. There were two floors, as I recall.

THORP: There were two floors. What we ended up doing was having basically two programs. We had our subacute care downstairs. We later received federal funding to do a Ryan White program that was transitional living, so our transitional living program was upstairs, and we had two different sets of staffing. The staff on the first floor were just taking care of the first-floor patients.

SCHWARTZENBURG: So you get through all of that prepping, the doors open, you start seeing pediatric patients?

THORP: We did start with pediatric patients, and it didn't take us too long to figure out that we had tremendously restricted ourselves or overestimated the —

SCHWARTZENBURG: The need?

THORP: I think the need was there. What we discovered was, just like the parents aren't always interested in stopping treatment, neither are the doctors, and so the doctors were very skeptical of transferring their patients anywhere where they weren't able to see them every day — morning, noon, and night — and keep that close control over them. We quickly realized that we had limited ourselves by restricting our facility just to pediatrics.

We regrouped, and I have to say, I think that was one of the things that CASA was able to do. It was always a challenge and it was a struggle, but we did try very hard to adapt, and as we saw needs changing and as we saw what was going to keep us viable as a facility we were able to make changes. As we opened in 1985 and realized that we needed to serve more than pediatric patients, we also realized that AIDS was becoming more and more of an issue where care was needed.

I think one of the initial conversations was with a Catholic priest that came to Richard Plessala, one of the major, major, major drivers and forces of CASA, and spoke to him about the need for AIDS patients. That started us thinking. Of course, that was a big leap from pediatrics to taking care of AIDS patients. The thought was, just not to limit ourselves to pediatrics, still go with that terminology of catastrophic terminal illness, still go with a concept that we were going to use

hospice concepts of care, but we were not going to limit treatment. Again, we thought it was very meaningful for the AIDS patients who would probably want to continue aggressive treatment but not necessarily need to be in an acute-care setting to get that aggressive treatment.

And so we did. We expanded ourselves. We had to go back to the state to get approval to take care of adults, not to be limited to pediatrics, and we then spread the word that we were going to be taking care of individuals with catastrophic terminal illness. Our identity was often confused. First we had identified ourselves as a pediatric facility and people automatically said hospice, so we were identified as a pediatric hospice. Then when we said that we were expanding and taking care of any individual, any age, with a catastrophic or terminal condition, there was still confusion as to who we were, what we were doing.

"Are you a hospice?" "Are you not a hospice?" "How are you licensed?" It was difficult to say we were licensed as a special hospital when nobody knew what that meant. And so we would have to define "special hospital." Then we would have to define our facility and how unique it was. Identity was always a little bit of a struggle as far as being able to explain to people who we were and what we were and how we did what we did.

SCHWARTZENBURG: How long did it take to get the word out? Which hospitals were transferring patients over to you? Who was seeing patients with AIDS?

THORP: It was more the case managers. I also shared with you a lot of the materials about that time. Actually, backtrack. That's not true.

In 1985, when we first started, people did not necessarily want to take care

of the AIDS patients. Quite often we were getting the patients because nobody else wanted to take care of them, and so we were getting many referrals either from the hospitals, who at that point did not have special units all set up for the AIDS patients. So, often we would get the referral from the hospital. The insurance companies that worked with us knew that we were very cost-efficient; that we did not have the overhead of the acute-care hospitals and we had priced ourselves to be a cost-effective alternative. Many of the case managers who listened and got to know us were making the referrals to us as a cost-effective alternative.

SCHWARTZENBURG: What did you do about ancillary services? Lab? X-ray?

THORP: Lab, we had a contract, and quite often we would contract with Woman's [Hospital], which was the closest hospital to us at the time. If they needed extensive work, we would have to transfer people out for an X-ray, but as far as a portable chest or looking at an arm fracture or whatever, we could do portable X-rays. Physical therapy/occupational therapy, we had on-site. What else? Pharmacy, we had on-site, so we had our own pharmacy right there and were able to do everything. We had IVs, TPN [total parenteral nutrition], chemotherapy right there on the premises. Instrumental to that was our chief pharmacist, Bill Bradley, who was also very involved in the development of CASA.

SCHWARTZENBURG: What about the nursing staff that you hired? I'm assuming you hired them on assuming that you were going to be pediatric, and then as you made the transition to AIDS, were there any issues with that?

THORP: Some stayed and some didn't. I'm thinking back. As we were starting, we started with a small staff, so I don't think we were talking large numbers that had

to be involved with it. For all of us making that transition, we were dealing with the same issues that the world was dealing with. So as far as even the administrative staff, myself included, it was a matter of so much that wasn't known about AIDS, and what did we have to be worried about? What did we not have to be worried about? The disease that we were dealing with was a puzzle.

The majority of people on staff were straight women who were not used to dealing with a gay population, and so the transition was not just from pediatrics to adults with AIDS. It was that whole gamut of all the issues that were going on.

One of the challenges of hiring staff was our unique facility. We were a small hospital. We were really a little bitty fish in a great big pond. The Medical Center was towering over us, and here we were, this little subacute facility. With that, as far as staffing was concerned, it was always a challenge because we were small, we could not offer the same salaries, we could not offer the same benefits as a lot of the big hospitals. Then with that, we were dealing with AIDS, which many people were still very skeptical and fearful of working AIDS patients.

Staffing continued to be a challenge, not just because of AIDS, but because of all the other issues that we were looking at. Many of our nurses were gay. And yet a lot of our nurses were straight and thoroughly enjoyed the work that they were doing. We did try to provide the flexibility and some of the other benefits that you can't get when you're working in a big facility, so we tried to compensate. Staffing is a challenge, no matter where you work. You're covering a facility 24 hours a day, seven days a week, and that's a challenge.

So we made the transition. We made the transition to take care of AIDS patients, but at the same time, we were also taking care of cancer patients. We

did a lot of oncology work. Through the years, we also started doing a lot of work with the elderly who were going through different orthopedic procedures. We were doing a lot of rehab for hip replacements and knee replacements. Many within the elderly population had multiple other health issues that they were dealing with that couldn't just be sent home for rehab or sent to just a nursing home for rehab; they needed the higher level of care that they could get at CASA.

SCHWARTZENBURG: Didn't need TIRR [Texas Institute for Rehabilitation and Research].

THORP: Right, they didn't need TIRR, but they still needed something a little bit more acute.

I maintain that CASA probably — well, I don't know how much, except we educated a great many people in the straight community about AIDS. It was amazing. We had this little apartment complex with an outdoor courtyard, and so people would congregate at the gazebo and people would congregate in our rec room.

Little old Grandpa who had his wife — again, another vivid memory: little redneck Grandpa, overalls, the whole nine yards, sitting right next to the gay man. Grandpa is losing his wife of 50-plus years, and the gay man is losing his lover, and they're sitting there sharing. You know, death is an equalizer, and it doesn't matter who's dying of what. They were able to share, and they were able to understand each other as individuals.

That would happen over and over and over again. I think that was missed quite often in the hospitals as they set up the AIDS unit and then the oncology unit and what have you. So often people don't get to come together and share

their stories and support one another. At CASA, they would. They would sit out there and share, laugh and cry. It was amazing. It was amazing to watch, but it would happen.

SCHWARTZENBURG: That's so touching.

THORP: It was. I mean, we had parties. Anytime a holiday came around, we would have to have a barbecue outside, or dress up for Halloween, or whatever, and so people —

Gretchen Thorp, Halloween, 1991.
CASA, Houston, TX.

SCHWARTZENBURG: I bet that got interesting.

THORP: That got interesting.

SCHWARTZENBURG: Halloween is very interesting.

THORP: Actually, everybody was very tasteful.

SCHWARTZENBURG: With the apartment setup, would that allow — you spoke of husbands and lovers being there. Would they be able to stay there in the —

THORP: They moved in.

SCHWARTZENBURG: They did?

THORP: They moved in, which was another huge draw, benefit. They moved in. It was a fully equipped kitchen, and so they didn't have to eat out in restaurants. They were able to fix their meals right there. They were able to be there. It got crowded, but there was a Murphy bed in the bedroom so that family and friends could pull down the Murphy bed and have a bed to sleep in. The patient had their bedroom, the patient room, but a family member could come out to the outer

portions of the apartment and be comfortable while the patient took a nap or had treatment. The family could all gather at any time, and they did. They would have a Thanksgiving holiday. When somebody is in the hospital for Thanksgiving, what do you do?

SCHWARTZENBURG: Right, you want to be there.

THORP: You have a turkey. So they could. They would set up, and they would cook, so it was amazing.

The other part of it was, from the rehab side, whether it be an AIDS patient getting rehabbed to the point that they could go back home or some of our orthopedic, or any of the patients, as far as rehab perspective, they were in that homelike environment with a fully equipped kitchen, so as far as regaining skills, testing out their skills and what have you, they were able to do it right there.

SCHWARTZENBURG: The ultimate occupational therapy.

THORP: Right, they didn't have to go to the therapy room to play in the play kitchen to make the toast and show the therapist that they could make the toast. They could do it right there, and they did. That's how they learned. I think it was also the motivator in the sense that they had somewhere to get out of bed and either go out into the living room or to go outside. It was not a big deal. You didn't have to get in the elevator and go downstairs to get to the patio to go outside. You would just get out of the bed and —

SCHWARTZENBURG: So many benefits.

THORP: There were a tremendous amount of benefits.

SCHWARTZENBURG: How long did people usually stay? I'm sure it ran the gamut, but just typically?

THORP: It did run the gamut. Probably, probably, the average length of stay would have ended up truly being maybe like 15 to 20 days, but we had some people that were there months, a lot depending on obviously their progress, but also on the case managers with whom we were working. We had some case managers that used us all the time and recognized the fact that we were able to provide the care that was needed, but also do so in a cost-effective manner, and rather than sending somebody home and having them end up back and forth in the acute-care hospital, that it might be just as well to leave them at CASA for a period of time to see which direction we were headed.

SCHWARTZENBURG: What was the experience? Did people get well and go home? Did they die there? What was the split?

THORP: I don't know what the percentage was, but we had a lot of deaths. We had a lot of deaths. I remember, we had a lot of successes as far as people being able to go home.

SCHWARTZENBURG: Did you have people leave, come back, leave, come back?

THORP: Oh, yeah.

SCHWARTZENBURG: Do you ever direct admit?

THORP: No.

SCHWARTZENBURG: Just from home?

THORP: Well, sure, yeah, if a doctor would call. Not as often. I would think that that was a rarity; that more often than not, they wanted them to be in the acute care just for a period of time to see what was going on.

SCHWARTZENBURG: Right.

THORP: And again, to do all the testing. We could do the testing, but it was more of a

challenge, and they could get quicker results if they admitted them to the hospital. Sometimes if there was a known treatment plan, if somebody just needed to come in for chemotherapy or something like that, we could get a direct admit and take it from there.

SCHWARTZENBURG: How did the staff deal with the death and dying?

THORP: The death and dying? We did use and we truly stuck to a hospice plan of care. So, even though we were doing aggressive treatment, we still had our social worker on staff, we still had a chaplain on staff, we still approached everything as an interdisciplinary team. We had weekly case conferences, so we would sit down as a team and go over the patients. I think a lot of that, in and of itself, was supportive. We had the social worker that was there; that if anybody, any of the staff members, felt like they needed to talk to the social worker or the chaplain, they could do that.

We did lots of the parties, and we did lots of the memories, so we had scrapbooks coming out the gazoo. We took pictures all the time, and we would go through the scrapbooks and the memories. And then we did an annual remembrance. We did an annual memorial service, and we'd invite family members to come back and to share and to see the staff again and what have you. I think it was just staff being supportive of staff more than anything else that made it happen, and family members. We had a lot of family members that so appreciated what we were able to do and even in a loss were appreciative and would come back and thank the staff for what we were able to do.

We were small. It was intimate. You really, really got to know the patients. You really got to know the families. We were all in it together, and we

were all supporting one another.

[END OF AUDIO PART 1]

SCHWARTZENBURG: Tell me about the families and their knowledge of, acceptance of that their son was gay and maybe not knowing that until they had AIDS.

THORP: Full gamut. We had those that were so, so supportive, and then we would not see some of the family members at all. That was just a given, as far as I'm concerned. As a straight woman, my education was watching the couples that would come in and care for one another, and the support that was there was just tremendous. I'm not saying that that wouldn't happen in a heterosexual couple, but it was amazing to see the support that was being given and the love and caring that was going on. Family members, it was just the gamut. To the best of my memory, I don't remember us ever having any kind of scene or event or what have you. We heard a lot of stories that a mother or father was not there because they disinherited their son years before, when they discovered he was gay.

SCHWARTZENBURG: If they were going to be there, they were there.

THORP: If they were there, they were there. If not, they weren't. I think for the most part, anyone who did not have a family member, immediate family member there had already either accepted or worked through that or was in denial, not addressing it.

SCHWARTZENBURG: Did you ever have any issues with care of the body after someone died?

THORP: I don't think it was related to AIDS. I mean, we had some funeral homes that were certainly much more respectful than others. We might have had one, and I think it was a cardboard box. They came to pick the AIDS patient up in a

cardboard box. [Sad pause]

SCHWARTZENBURG: I bet you wanted to say a lot, and I bet you didn't.

THORP: At that point, what do you do? I mean, because the family members are the ones that make the decision as far as whom to choose. That is one. I do remember that. I think I also recall the vehicle that the cardboard box was going in. The whole scene was not good. I don't know how the family came up with that decision of whom to call.

We never called a funeral home and were refused. We never had anyone say, "No, I won't come and pick up that person."

SCHWARTZENBURG: Two totally different thoughts. One, I was curious about physicians. You have to screen physicians. Did you have privileges for any physician that would apply, and they could follow their patients if they chose to?

THORP: Oh, absolutely, yeah.

SCHWARTZENBURG: Also, did you have physicians that had permanent privileges, and if the attending physician didn't want or couldn't get privileges, that the CASA physician would become the attending?

THORP: Any physician that saw patients at CASA had privileges. Again, we were licensed as a hospital, and so our physicians had to have staff privileges, so they had to apply for staff privileges. That was sometimes one of the reasons why they would not refer to CASA. It was just another place that they would have to go to see their patients, but yes, they did have an option.

Dr. Paul Gustafson was our medical director. If they chose not to follow their patient while at CASA, it didn't mean that they were turning over their patients forever and ever, but if they did not want to follow the patient while they

were at CASA, he would follow the patient while they were there. So they had that option that they could either apply for privileges and follow their patients at CASA or refer to Paul to follow them.

How many physicians? At any given time, we probably had about 20 physicians on staff.

SCHWARTZENBURG: That's significant.

THORP: Uh-huh. Again, of those, not all of them admitted all the time, but they had privileges and were able to admit.

SCHWARTZENBURG: The other question that I had was about attending memorial services. Did you do that often?

THORP: When I could, and I had listed that as one of the other things that staff did as far as coping. A lot of them did attend. I attended some, but just the time and timing was always so — probably not as many as I would have liked to, but yes, we participated in a lot of the services as well.

SCHWARTZENBURG: You mentioned that insurance companies valued the service that you were providing. Most of the patients, were they private-insurance pay, or did you have Medicaid?

THORP: We did not have Medicaid. We were not Medicare-certified. It was either private insurance, or we touched on grants. We had a grant from the Texas Department of Health to provide subacute care to AIDS patients, and that would have been on our first floor. We had Ryan White funding to provide what we called — a transitional living center, and what it provided was housing and support services for individuals who were HIV positive and homeless. That was on our second floor. With that, a lot of those individuals had problems as far as

substance abuse, and so we also tied in a lot of therapy as far as substance abuse.

SCHWARTZENBURG: You have a whole nursing curriculum in that one clinic.

THORP: That too was a mixture. We tried to educate the world, and it was interesting because some of these guys who were early on — I mean, they were just HIV; they had not been diagnosed with AIDS — they were actually able to see — again, we do parties and we do gatherings, and they're part of that, and they're able to see some of the challenges that could be theirs to have further on down the road. I don't know whether we were trying to use scare tactics to try to get them to shape up and get their lives together and clean up and quit abusing, but it made for some interesting company.

Gretchen Thorp teaching AIDS Awareness, Houston, TX, n.d.

Private pay, insurance. We did a lot of work with the HMOs [health maintenance organizations] and the PPOs [preferred-provider organizations]. We did a lot of work with Kelsey [Seybold]. We did a lot of work with Prudential, who again were really trying to manage and do case management and utilize alternative services, so we did a lot of work with the HMOs and PPOs.

SCHWARTZENBURG: What was your perspective in relationship to the Houston AIDS Alliance?

THORP: That's where I'm really stretching the memory. It was a very, very political scene, I think.

SCHWARTZENBURG: This was related to Ryan White money. Did you receive that? You did receive that.

THORP: We did, we did, so we were a part of it. I mean, we were a part of the political scene, and we were all fighting for money. It's so interesting to look back because I know that everyone initially was very, very interested in helping in this crisis.

As time went on, AIDS became a moneymaker and it was a lucrative business. Whether we're talking the HIV service providers — well, with that would be all the hospitals. Everybody suddenly was very interested. Again, when we first, first started CASA, we were getting AIDS patients because no one wanted to take care of the AIDS patients. As the years progressed and it truly became a lucrative business, people were fighting to take care of the AIDS patients. There were many, many, many people that were very instrumental and very involved and wanted to work together to address the problems of AIDS. Many of us, as HIV Service Providers, and that was the name of the organization that we formed, would come together on a regular basis to try to share and try to see how we could work together and go after funding, but also tackle problems as a united group.

Through the years, things escalated. A lot of egos got involved. I think as I look back, the service providers and the Alliance were getting hampered by power struggles and egos. Whether anyone was looking at the big picture was a

challenge. I think in my transcript[1] that I was in favor of the funding staying with the Alliance.

SCHWARTZENBURG: It appears so.

THORP: It appears so. Because we were working so hard. We were trying. Yet looking at it in hindsight and from overview, I hear exactly what Lindsay was talking about from his perspective.

Then the other piece of it, which I thought was interesting, was John Paul Barnich's testimony, which was probably very accurate. You know, Sue Cooper was wonderful. She had worked at Anderson. She was a wonderful social worker, and she did tremendous work with HIV and AIDS. But as far as being the executive director of the Alliance, it was probably a job that would have been better served by somebody with more of a business background. All that to say on hindsight, re-looking at this, I was in and amongst the ones that were trying to keep funding within our management group. But probably, probably it made more sense to have the county involved. It really did.

SCHWARTZENBURG: It made more sense to have a more equitable —

THORP: Global, yeah. Everyone that was part of that service provider — I mean, we were all in it for right reasons, but again, all the egos and all of the money was beginning to make — your eyesight was a little bit fuzzy after all of that time, and so probably to have a broader scope to look at the big, big, big, big, big picture was probably the better idea.

SCHWARTZENBURG: I would think that it would be easier to see that now versus

[1] Public Comment, Harris County Commissioners Court Minutes, July 21, 1992, pp. 19 – 33.

then, when you built trust amongst each other. It's like, "We're all in it together. We know that we can split up this money in a way that seems fair and equitable, given all that we do, and we just don't trust what the county is really going to do. How are they going to manage that?"

THORP: Right.

SCHWARTZENBURG: Then once the county put into place the checks and balances that they put in place, "Okay. It makes sense." But just that initial "You're taking it away. I don't know what happened with the medical records. I don't know what's happening with funding." It's more of a fear-based —

THORP: Fear of the unknown. You don't know what's going to happen, and we've been doing it all these years, and so we know what we're doing. Hindsight is 20/20.

SCHWARTZENBURG: Isn't perspective wonderful?

THORP: Perspective is great.

SCHWARTZENBURG: It's when you're in the middle of it.

THORP: If we could just all go back, though. I read the transcripts, and I said, "Isn't that interesting?" It is amazing. There were many, many people that were working so hard and were looking out for the individual, not the entity. We were talking big dollars. I mean, we were talking *big* dollars, and at that point things sort of get lost and perspectives get lost and egos get involved.

SCHWARTZENBURG: It really shifted with who was taking care of people with AIDS, because it wasn't the same mom and pops or the same small grassroots organizations. They probably weren't getting the funding after the county took over because it didn't make financial sense or it was too hard to provide the

oversight for that many.

THORP: For that many little entities, right.

SCHWARTZENBURG: What ultimately happened with CASA?

THORP: It just got to the point where AIDS was more treatable, and more and more individuals were living longer and living at home with home care, and so that census dropped. I mentioned that we had the contracts with the HMOs and the PPOs, and our contract with Kelsey [Seybold] changed. I can't remember the details of it, but at that time we were just trying to be realistic. We were definitely the little bitty fish in the great big pond and we realized that it was going to get to be harder and harder financially for us to continue and we would rather close than —

SCHWARTZENBURG: Die with dignity.

THORP: Yes, die with dignity, that's right, rather than provide a lower level of care or let our standards go down or anything like that. So we did. We just decided that it was time to close the doors.

SCHWARTZENBURG: What happened to patients that would have been there? Do you know?

THORP: We closed over a period of time. We announced ahead of time when we were going to be closing, and so we just did a gradual phase-out with the patients that were there. It was sad.

SCHWARTZENBURG: Oh, I imagine.

THORP: Actually, it was a mixed emotion. I think it was probably a mixed emotion for everyone that was involved. We were there from 1985 to 2000. To backtrack, when I started, I was director of nurses. Probably within the first year, I was

promoted to the administrator. With that, from my perspective, it was like 15 years, 24 hours a day, seven days a week being on call. We were small, and so if something went wrong, usually I was the one that was being called. Or if we were short-staffed, I was able to fill in a lot of times and what have you. So it was definitely an emotionally and physically exhausting period of time.

It was very gratifying. It was a tremendous experience. It was a huge learning experience as well as everything else. It was a wonderful opportunity. Again, the people, the patients and the staff that we worked with were pretty amazing. You have your challenges as far as staffing is concerned, but it was an amazing 15 years. Closing was sad, but again, it was okay.

SCHWARTZENBURG: Does being able to close around the time when it was turning around, survival was so much better then —

THORP: It was.

SCHWARTZENBURG: That's a good reason to close; that you're not needed anymore for your primary area of focus.

THORP: Right, right.

SCHWARTZENBURG: That's the sweet part. The bitter is, it's over.

THORP: Yes. In talking to individuals as I was trying to refresh my memory for this interview, it's amazing to me the progress that has been made in the treatment of AIDS in, I think, a relatively short period of time. It's a long period of time by certain standards, but for medical treatment, I think it was a short period of time that it took from AIDS being such a devastating disease to now being a chronic condition. It was horrible. It was just horrible. [I have] vivid, vivid memories of the symptoms and the diseases that were entailed with AIDS. It was

unbelievable.

SCHWARTZENBURG: My mom worked there [CASA] for a while, and she was telling me the story that she was helping a man get to the restroom, pivoting and walking with him, and she said fluids started coming out of every orifice, and just how —

THORP: Everywhere, right. And it would be constant. Anytime I get a little stomach upset and I'm miserable for a couple of days, I'll have a flashback and I'll think of those guys that had this all of the time. And then the Kaposi. The Kaposi was horrific. I remember the tremendous incontinence as well as the Kaposi. Devastating. I just can't imagine watching my body go through those changes. Along with everything else that they were dealing with, they were physically watching tremendous devastation to their bodies.

Let's go back to the Service Providers for a minute. People were working very hard.

We did touch on the lucrative business that AIDS treatment became. Before I close, I do have to say that I think it was very unfortunate that there was so much abuse that was going on with the overtreatments and the overutilization of insurance dollars. Dollars were so sacred at that time for individuals who either had no insurance or individuals that had limited insurance, and to watch those that had million-dollar policies and to have those million-dollar policies totally, totally used, one would question a lot of the practices that were going on at the time.

I had mixed emotions about all the specialty units that were set up in the hospitals. That was one of our challenges as CASA. We didn't have the glitz and the glamor, and we didn't have a dietician on staff that could make your special

pudding at midnight. Some of the acute-care hospitals that set up specialty units provided those services but the insurance money was actually paying for it, and I think there were some tremendous, tremendous abuses and overspending and overtreatment. I felt sorry for some of the patients who went through the excessive treatments that they went through.

SCHWARTZENBURG: Do you think that some of that was just trying to get as much money as possible, just to be crass about it? Or was there also not wanting to give up? Physicians not wanting to fail?

THORP: I copied for you an article that addressed the amount of money that was being spent in Houston. This was an interesting article because they were comparing Houston to other cities and how much less was being spent in other locations. But one of the comments from one of the physicians who was well known for treatment practices that seemed to be excessive was, "I'm not going to give up."

I don't know the answer to that, but it seemed if you looked at it historically and if you looked at it as far as trends, and trending some physician practices versus other physician practices, there was a dramatic difference between some of the practice standards. I think that was an unfortunate piece of what went on during that period.

SCHWARTZENBURG: There's always an ugly side.

THORP: There is. There is.

SCHWARTZENBURG: For all the good, there's always one or two individuals that just have not the best intentions.

THORP: Right. Again, who knows? I mean, the intentions might be exactly what we said. They might have wanted to do everything in order to try to fight.

SCHWARTZENBURG: Right, that was their belief system.

What do you think made you the right person for the job? It's so interesting how you got there.

THORP: I often say that, as far as my whole career. I sort of stumbled into it. I had many friends who had their trajectory. They knew exactly what they wanted to do. Two years here, five years here. I didn't have that. It worked out great, the way it worked out. I'd like to believe that I was the right person at the right time. I think others could have stepped to the plate and done the same job. I think some might have been a better administrator. I was more of a hands-on nursing type and I, like Sue Cooper, could have probably benefited from more of a business savvy to be the administrator. Somebody with more of an administrative business sense might have been the better administrator per se. I feel fortunate that I was where I was when I was there.

The 15 years that I worked at CASA were extremely rewarding. The work was hard, but I know that we did a good job. I can now look back and just feel good that at the time we were providing a service that was much needed.

SCHWARTZENBURG: I think we'll end on that note.

THORP: Okay.

SCHWARTZENBURG: Thank you so much.

THORP: Well, thank you for giving me this opportunity to share and reflect.

[END OF AUDIO PART 2]

[INTERVIEW CONCLUDED]

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