



*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 # 033

An Interview With
Jane Nelson

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AN INTERVIEW WITH JANE NELSON

LYNN SCHWARTZENBURG: This is Lynn Schwartzenburg interviewing Jane Nelson for The oH Project. The interview is taking place March 27th, 2017 in Houston, Texas. I'm interviewing Ms. Nelson to document her recollections concerning the response to the HIV/AIDS epidemic in Houston.

Good afternoon.

JANE NELSON: Hello.

LYNN SCHWARTZENBURG: Welcome. Thank you for doing this.

JANE NELSON: Thanks, Lynn. Thanks for asking me to.

LYNN SCHWARTZENBURG: Tell me, when and where were you born?

JANE NELSON: Here in Houston, a million years ago back in 1951, at St. Joseph's Hospital. My first home in Houston was in the Montrose in the Museum District, on Milford Street.

LYNN SCHWARTZENBURG: Tell me about your parents.

JANE NELSON: My dad, Lester, worked for a mechanical contracting firm throughout most of my life. Actually at that point, he was trying to have his own building company, and he was involved in the building of our home on Milford Street. The house is now long gone. A big one has been put in its place, but the property still exists.

My mother was a 1950s homemaker. She was a little old for the time, I guess, to have a child. I was their first child, and she was 40 when I was born. She was six years older than my dad. My early childhood was very much spent at

home with my mom. I was the only one. I actually have a lot of memories of my mother, though she did die when I was barely six years old. She was diagnosed with pancreatic cancer in the spring, and she died just before Thanksgiving that year. I had turned six in August. That was a huge loss that defined basically the rest of my life in a lot of ways.

SCHWARTZENBURG: What happened then after she died?

NELSON: After she died, my dad and I moved in with his mother. She lived in the Spring Branch area. She was a very abusive person. She had been abusive of my dad when he was young. He was a child born in 1917. I don't know how much he identified her abuse, but he told stories later, when I was older, of horrid things that she did to him: locking him in closets, and making him crawl across the floor to beg forgiveness if he wronged her.

Life there with her — I think we were there about a year — it was not a happy time. I was grieving the loss of my mother and living with a woman who was very, very cruel.

SCHWARTZENBURG: Were you in school?

NELSON: I was. I had been going to school first at Edgar Allan Poe Elementary in the Montrose area. Then we were in Spring Branch; went to I guess it was first grade there.

Often when I would come home on the bus, she would have locked the doors and I couldn't get in, so I would either sit on the step and wait for my dad to come home after work, or I would go down the street to a neighbor's. The neighbor's mother — this was a schoolchild that I went to school with — the mother clearly kind of knew what was happening because she would let me stay

there. Even though we would sometimes see my grandmother, whom I called Nana, walking down the street looking for me, she would let me stay until my dad got home because she knew I would be punished.

We were there until Nana got angry at my dad about a year or so later. At this time, I think my dad had already begun to date my stepmother, though they only knew each other six weeks when they married. School was almost out for the spring semester, but Nana kicked us out of her house. Dad took me to my teacher's. I lived with my teacher for about a week. She found another family, of a fellow student, and I went and stayed with them until school was out.

Then after school was out, my dad and mom got married in July. I don't really remember knowing my mother until they were already getting married. She had a daughter. She had been living with her parents here in Houston. They were introduced through some mutual friend that my dad knew from his work. By then, he was working for the Warren Company, the mechanical contracting company. That was how we started life, with my mom and her daughter Wendy, who was 15 months younger than me, and my dad and me. They had a lot of growing as a couple that they needed to do, and Wendy and I were thrown in the middle of this pretty chaotic and not always happy time.

SCHWARTZENBURG: Did you and Wendy get along?

NELSON: Most of the time, yes. We were often allies. As our parents fought, we were allies. Then of course, like any siblings, I guess, we had our times too that we fought. Actually, Wendy and I stayed pretty much friends as well as sisters until later in life, when she started getting involved in drugs.

That was our family until my mom got pregnant, and then she had my



Mark Nelson on his 7th birthday,
July 24, 1968.

brother Mark. Mark was 10 years younger than me, nine years younger than Wendy. He became the two girls' little baby, but he was challenging. He was ADD [attention deficit disorder] before anybody really knew about ADD. I can remember throughout his childhood, I took a protector,

maternal role with him, I guess partly because of the

age difference. Also, my mom Audrey worked. I guess some of that probably played into that as well; that I was the oldest. We always had a grandparent around. My mom's parents and grandmother lived just down the street, so they were always available to us.

SCHWARTZENBURG: How would you describe your childhood?

NELSON: A mixed bag. Of course, I'm sure I've, in a lot of ways, idealized my mother because I had her for such a short period of time, yet my memory of her is that she was always loving, very kind and gentle. My dad very much validated that later in life, when I would ask about her. After my mother died, I guess — again, this is the 1950s — people didn't talk [about feelings], they thought children would forget, wouldn't know, so it was not discussed. That probably is not the best way to handle a loss of that type.

Audrey had a very different type of mothering. She was not a warm-fuzzy. She still isn't. That was a big change for me. She and my dad would have us two girls pitted against each other, "That's your daughter. That's my daughter," so the family did not blend easily. We lived comfortably. We were in a middle-class home. We had all those things. It was not always the warmest

home. My dad provided probably more emotional warmth for me, though I don't think that was true for my siblings. I was always raised to be the good girl and to watch the younger ones, and do the right thing, and set a good example. It's a curse that has stayed with me ever since.

SCHWARTZENBURG: Being the oldest still.

NELSON: Yes. It is the good-girl curse.

SCHWARTZENBURG: Tell me about high school.

NELSON: I went to three or four different elementary schools because of moving various places, but in junior high and high school, that stayed solid. What really made the difference was that we started going to White Oak Baptist Church.

I met a friend; her name was Peggy. She's actually my sister-in-law. She's Deb's brother's wife. I met this friend, Peggy, and she went to this church, and so I bugged and bugged my parents that I wanted to go there. We all started going as a family, and that's where I met my group of friends. We also all went to junior high and high school together. This was seventh or eighth grade. Our connection was really through church, which was good in that probably it kept us all out of trouble for a long time because we were good little Baptist kids, but later it became quite a curse for me as I tried to reconcile being gay with what the Baptists said about that.

In junior high I met Deb, my wife. Of course, we were just pals, and she would sleep over, and we all ran around as pals. I dated her brother for a while and was clueless, just clueless about the fact that I wasn't just straight and narrow.

That was at Black Junior High and Waltrip High School, and then when I graduated from there, I went to Houston Baptist University. My original major

was English. I wanted to write the Great American Novel. I was going to be a teacher. I know women my age did a lot of other things, but this was back in the 1960s, in the, “Are you going to be a teacher, a nurse, or a mother?”

SCHWARTZENBURG: Traditional roles.

NELSON: Yes, very traditional. Ultimately, I switched from being a teacher to a nurse.

That’s how I became a nurse. It wasn’t like any sort of, “Oh, I’ve always wanted to do this.” My friend who lived across the street, she and I were the same age. We went to college together; knew her from the church. Her mom was a nurse, and one day she kind of said, “You guys should think about being nurses,” and so we kind of went, “Okay,” and switched majors and went into nursing. Graduated in 1974.

Actually, in the meantime, Deb and I both met guys. I had actually begun to realize I had an attraction to Deb, but I denied it, as she also denied her feelings for me. We were just good friends, and we were going to get married and have kids and be best pals forever.

SCHWARTZENBURG: Live next door.

NELSON: Yes, yes, live next door, and that would be fine. No, that didn’t work out. So

Deb and I both got married to these men. She and Neil were married for about a day. Deb figured it out much faster than I did that this was not the life that was going to work for her, and so that ended. I went ahead and married Rod. I was married to Rod for three years, but we only lived together for two of those years. After we separated, I immediately moved in with Deb, and I’ve been with her ever since.

SCHWARTZENBURG: What was your first job after nursing school?

NELSON: At first I worked for a psychiatrist. He had an office up off of the 1960 area.

The reason I was out there was because Rod and I, in an effort to save our marriage, had bought a house, because that always works [sarcasm]. So we had bought this house out in that area, and I had a job out there. I worked for a doctor for about a year or so, two maybe, but by then, of course, I was back here in Houston, not that that was far away, but it was a 30-minute drive or so, though it was much better than it is today.

I began to think about trying to find something closer to home that hopefully paid a little better, because I was making \$450 a month. Of course, this went a lot further back in the 1970s. I found out about a job at M.D. Anderson. I got a job at M.D. Anderson [excitedly]. I went and interviewed, and I was thrilled. Deb and I were like, “Oh, my gosh, we’re in the money!” because I was going to make \$918 a month. My job was to work in the outpatient chemotherapy and emergency area. This was back in 1977. I started work on Valentine’s Day. Of course, our patients were all M.D. Anderson cancer patients, so we started IV’s [intravenous] and gave them their chemotherapies and saw people who came in with various problems related to their cancer.

This ties into our discussion about the AIDS epidemic, because in 1979, before I’d even heard of AIDS, GRID [gay-related immune deficiency], HTLV-3 [human T-lymphotropic virus type 3], HIV, or anything, there was this man who was brought in. I may be wrong, but my memory is that I was working evenings. I worked all the shifts, different shifts. I think I was working evenings, and this young man was brought in. He was an exotic-bird importer, and he lived in San Francisco. He was brought in for admission. We’d get people, off-shift

admissions that would come through the ER [emergency room], or people who were scheduled to be seen in clinic in a day or two that were too sick. This young man was very sick. He had all sorts of strange opportunistic infections.

I can remember, all the doctors were like, “What the heck?”

People were like, “Well, it’s like he’s got this stuff from the birds, but why would his immune system be so low, and why would he have gotten this?”

So this gentleman, I remember he was a young gay guy, was admitted, and we learned, we heard through the grapevine, that he died just shortly thereafter, like within a few days.

SCHWARTZENBURG: After he was admitted?

NELSON: Yes.

SCHWARTZENBURG: Now, did you know that he was gay because of gaydar, or did you know because he self-identified, or —

NELSON: My memory is that he was there with a partner; that they were open. I don’t know if I’ve invented that part or not, but somehow we knew he was gay. I remember it being like a statement, not like something that we all speculated, so I think we knew it somehow. Either there was a partner present, or he simply said it in his history. It was very baffling to everyone involved as to what was going on [with his health].

SCHWARTZENBURG: Did you just tuck that away in your memory or forgot about it until you started seeing more AIDS patients?

NELSON: Yes, it was sort of more that. I remember at the time that it felt like an unusual event, and whenever there was something kind of out of the ordinary, it sticks with you.

I digress, but we had a lady who had taken angel dust, PCP [phencyclidine], and nobody knew she had taken angel dust. They all thought she had a brain tumor. She, I remember, kicked one of our doctors in the chest, and this was a very substantial man, and she pushed him across the room in the ER because of this kick. See, again, this is something that has stuck with me all these years because it was like, “Whoa,” and then we found out [about the PCP]. We were all thinking, “Oh, this poor lady. She’s so confused.” She had taken these serious drugs. At any rate, that’s not really here nor there.

SCHWARTZENBURG: But that’s why you remember.

NELSON: This was sort of one of these events. It was an unusual event, and I guess the fact that he was gay, I had that, “Wow, what’s going on?” connection feeling.

SCHWARTZENBURG: I wouldn’t imagine M.D. Anderson really saw that many [self-identified] gay patients ordinarily.

NELSON: If they had cancer.

SCHWARTZENBURG: Sure.

NELSON: Lynn, back at that time, we weren’t even all out to each other, much less would we necessarily have a patient who would be that open. Those were kind of defining characteristics that were a little out of the ordinary. We may have had 5 million gays a day that we didn’t know, because we weren’t even telling each other. Ultimately that changed. I don’t know if the AIDS epidemic even helped with that, seeing more and more AIDS patients. That was the first time that I believe I saw an AIDS patient, though he certainly was not identified as such.

During this whole time was my own coming-out process. I came out to my parents. They rejected us totally, even though they had known Deb for a

decade, and we were not welcome in their home for over a year. No one spoke to us. That was probably one of the freest times of my life, looking back. This whole personal process was evolving while this thing, this disease was happening to the community.

I also recall that before AIDS, there was a division between the women and men in the community.

SCHWARTZENBURG: Tell me more about that.

NELSON: Early on, there were probably a half dozen nurses that I worked with that were lesbians, but it did take us all a while to say that to each other. Once we did, we were all much happier. We were like pals, but there weren't that many men that were a part of our group. I remember even we would want to go out to go dancing, and we'd go to a club. The Depository was one, the Farmhouse, the OP [Old Plantation]. These were all the [gay men's] bars back in the day, and there was this time that if you were a woman going in, "I need to see two picture ID's."

"Oh, you have two picture ID's. I need to see a third one."

"Oh, you have on open-toed shoes. You can't come in."

Oh, we would get so angry, because they would turn us away. Those walls broke down once this health crisis hit everyone and we all began to work together to help one another. It, I think, maybe even sped up some of the coming-out process for some of us.

The reason I was having this coming-out crisis with my family was that my sister, Wendy, was now married, and she had a little daughter, Jennifer, a little baby. Wendy left her husband and came to live with Deb and me, with Jen, and we helped take care of Jen. Her husband decided to sue for custody of Jennifer.

Don't exactly know why. Don't think he would have really wanted the responsibility. I think it was more a revenge thing to Wendy. But he decided to name Deb and me as part — he was subpoenaing us to testify because he wanted to prove that Wendy had put Jennifer in an unsafe environment [by living with lesbians].

For someone who wasn't really even out yet except to a very small handful of people and not to my parents, this was very, very stressful. Ultimately it's what pushed me to tell my parents. It was unfortunate that they took it so badly, but I didn't want them sitting in a courtroom hearing me testify.

The custody hearing was held. The subpoenas did get served, although we dodged them as long as we could. I did have to go on the stand, but it was actually not a bad experience. It went okay. Wendy got custody. Several jurors came over to us after the whole thing and said, "We were never going to give the custody to him. This was clearly such a revenge thing." That was very gratifying, and they were very supportive of me in that. So it was a positive experience in the long run, though very stressful in the short term. This was all happening in 1979.

Then 1980, and that's when we started hearing about this new gay cancer, Kaposi's sarcoma, the gay cancer. Old men, what? What are these young men doing with this? We began to hear about GRID, gay-related immunodeficiency, or immune disorder. I forgot which way it was. HTLV-3, this virus. And then, of course, ultimately, acquired immunodeficiency syndrome, and we began to see more and more patients at M.D. Anderson.

SCHWARTZENBURG: Why M.D. Anderson?

NELSON: I think the majority at least started there because they either had lymphoma or KS or some form of cancer that was a part of this. It seems to me that we then began to see patients who maybe didn't have the cancers yet. I'm not sure about that, but I think that's the case, I suppose because they didn't know where else to go.

SCHWARTZENBURG: Was there a special floor for AIDS patients?

NELSON: What developed was, Peter Mansell, Adan Rios, Gary Brewton, Delia Chuitan, this group of physicians became sort of an add-on to one of the clinics; that they begin to see the patients in clinic there. I was still in the chemotherapy/emergency area, and so we would see them as they came for their treatments or because they had some illness that brought them into the ER.

I had a friend, Chella, who worked with Dr. Mansell directly, and then research protocols began, testing the drugs to try to figure out what could be done for this horrible thing that was happening. And personally, outside the hospital; we're watching these young men drop like flies in the hospital, but also outside the hospital. The gay men that I knew, we began to see — like Ronnie, got sick and he died, and we went to East Texas, to this horrible religious funeral where we all clumped in the back like little outcasts, thinking, "Sheesh." That kind of thing started to happen more and more; that we would hear about a friend who was ill.

We also made friends with our patients. I know the professional boundaries are much stricter now, but back then we crashed them all the time, and it wasn't really looked at as stringently. I'm not sure that that was the best thing for our patients or for us, but it did lead to more socialization and becoming

friends with more people whom we then sadly often had to watch die nine times out of 10. That all was at M.D. Anderson, and I was a part of, in my role there providing chemotherapy treatment, until 1983.

SCHWARTZENBURG: Let's go back, before we leave M.D. Anderson.

NELSON: Sure.

SCHWARTZENBURG: What was the attitude like towards AIDS patients? For the people working at M.D. Anderson that were gay or out or even not out, I'm sure that they were fine with dealing with AIDS patients, but what about others that may have worked there? Did you notice a difference?

NELSON: Well, yes. I really have been thinking back on this time, and yes, within the group of those of us who were gay and lesbian, we didn't have this aversion, but we had fear. This is back when we didn't even wear gloves to start IV's. None of the protocols existed, although for chemotherapy and for infection purposes it certainly should have been. It was, I guess, a more naïve time.

I can remember we had a nurse who was pregnant, and we all said, "Oh, don't go around them. Don't take care of them," because none of us were sure.

And she said, "I'm not going to."

Yet I understand that. I don't identify that as homophobia as much as —

SCHWARTZENBURG: Self-protection.

NELSON: Yes, "I'm going to protect this child."

Back then, I was the nurse manager, and I was pretty much out by then to everybody at work, and I don't recall people overtly in my presence ever saying or doing — any of my staff saying or doing anything that was questionable as to how they would handle the patients, but I do remember hearing that not every unit

was that way. I would suppose that probably not even every person on my staff was quite as forthcoming as they should have been. They just didn't tell me. I do feel like if anything really big had happened, I would have heard. I'd like to think that. I like to think we had that level of communication, if not by the person who did something wrong, by someone else. They often reported things.

I know that overall, these patients were the bottom of the line in terms of care. M.D. Anderson, back in those days, everything took forever. I can remember a patient in one of our waiting rooms said, "Boy, the thing about this place is you don't have magazines in your waiting room, you have novels." It was true. There was this rolling stand of paperbacks. He was like, "And I see why." Wait times were really, really long. I do believe that for our AIDS patients, they were pushed back even further.

Some of it may have been homophobia. Some of it may have simply been, again, fear and ignorance, and we all were fearful and ignorant because nobody knew. Nobody knew exactly for sure what was the mode of transmission? Where did this come from? How did it start? Could I get it if he coughs on me? Could I get it if I pick up a dirty tissue? We all had this fear because nobody wanted to get sick and die. I think it was twofold. I'm sure there were people who were — because I know there are still people who are — homophobic and who would just as soon not look at any of us, much less have to deal with us. I also think some of it may have been purely driven by fear and ignorance, not about gay people, but about the disease.

SCHWARTZENBURG: In your unit, people were diverted to different parts of the hospital, so it really wasn't long-term.

NELSON: Exactly.

SCHWARTZENBURG: You would hear that someone had died, more so than really —

NELSON: Yes, unless, of course, it was someone I'd gotten close to, and then I would typically — all of us did; we'd go visit them in the inpatient unit. I remember one person in particular. Louie was his name. He had the big handlebar mustache. The stories about the guys are just — we learned all sort of things from these guys with things that they would share with us about their personal lives. Not everyone was happy-go-lucky, but so many of them were. That was the incredible thing; that here you are with just wasting away to skin and bones, but you're still just coming in [snapping fingers], "Girl," and laughing and snapping and just having as much fun as they could with life at that point until finally they couldn't breathe or they couldn't walk or the pain was so great.

Louie was this big, tall guy. I think we thought of him as a leather guy. Louie by then, he was this tall guy, but he was a very thin, gaunt tall guy. He had been admitted, and I remember I went to see him. This was one of the hardest moments that I remember from there [M.D. Anderson]. He was like, "I'm just so afraid of what's coming next."

I said, "You mean?"

He said, "I mean next, after this life. I'm just so afraid. I just wish somebody could tell me what there is, what's next."

I said, "Louie, none of us really know. None of us know."

He just was crying. I knew he didn't have long at all.

I just told him, "Well, wherever next is, I'll see you there one day if there is a next, if there's a place to be."

He was like, “I don’t know about this heaven, and they tell you all this stuff in religion.”

I just said, “If those people that are telling you that you’re going to hell are right, you’re going to see a lot of us there with you, and it won’t be hell because we’ll all be together. It can’t possibly be.”

Then he was like, “Well, this is already hell,” and it was.

I remember that moment, and I remember his fear. I remember wishing I had some comfort to give him.

That was Anderson, but I always had kind of these same — it wasn’t with only those guys. It was with my cancer patients as well who didn’t have AIDS. Somehow, I always got connected to one young fellow or another, gay or straight, and just always had some sort of experience like that. I guess that was part of being there, for me, was to try to just be there for them.

SCHWARTZENBURG: Was there ever anything in your youth or your past that prepared you to deal with so much death, because not everybody would choose to continue to be there, but you found something in your work that was fulfilling and that you had something to offer, even though it must have been very, very painful to see people die, not just of AIDS, but of cancer too? The death rate is not much better for cancer than it was for AIDS? Why you?

NELSON: The only thing, I guess, retrospectively that I can connect is my own mother’s death. She died at M.D. Anderson. I was just a little kid, and I couldn’t really be there for her. Then after she died, it was just like she hadn’t existed in some ways, because nobody talked about her, so we just went on, and I got this new mom and new sister and new brother. Maybe that was part of it, was kind of

trying to figure it all out or be there for someone else.

SCHWARTZENBURG: And to remember. Make sure that people aren't forgotten.

NELSON: Yeah. I did stay, and I did find the work rewarding yet sometimes pretty painful.

In the middle of this, of being there, Deb decided to become a nurse. She was a teacher. So, we put her through nursing school. I worked, and she went to nursing school, and then she started to work at Anderson too. I was still very enthused about nursing back in those days. "Come on, be a nurse with me." It was like not something I had decided was going to be my life's calling, but I did like it. I liked the work. I liked the people I worked with. I liked that feeling of doing something that mattered, that maybe made a difference. I guess that was what kept me there. That caretaker part of me was very satisfied by being able to do that. Then I guess even becoming the nurse manager, well, once again, the big sister, now to 45 people, 45 employees, I think that's what kept me there for a while until I left. That was in 1983.

SCHWARTZENBURG: Why did you leave?

NELSON: Because Deb and I decided to see Alaska. We decided that we were going to go on an adventure. Back then, you could take your teacher's retirement money,



Jane Nelson with pop-up tent and Toyota truck, 1985.

which in later years, when I came back to Anderson, I paid back. I took my teacher's retirement money that I had put in for those years, and we bought a little pop-up camper, and it was little [emphasis], and a little Toyota pickup. By then we had these gay boyfriends, Ian and Lane. Ian worked with me. That's how we met. Ian and Lane and Deb and I were going to do this adventure and go to Alaska.

The guys crapped out on us. They didn't go. They stopped in Seattle and moved there. Deb and I quit our jobs. We did pack up our little puppy, our little schnauzer, Rocky the Flying Squirrel, and off we went. We stayed off work. It was very cool. It was a lot of fun. It was a challenge in another way.

We drove the ALCAN. Back in the 1980s, the Alaska-Canada Highway, the ALCAN, was pretty rugged. We drove up, took time all the way to get there, then drove back down, and we had this job lead about Cedars-Sinai. One of the nurses that had been my manager had taken a job at Cedars-Sinai at an outpatient cancer clinic and wanted us to come work there, so we decided maybe we would do that. We went down and we interviewed and saw it and everything. "Yeah, let's do this."

Came back to Houston, kind of got our stuff together. On the day that the Challenger exploded, I remember that day we were on an airplane flying. Jennifer, who was my niece, Wendy's daughter, said, "I remember that we took you-all to the airport, and I remember I was crying and crying because I couldn't believe you guys were leaving me. When I got to school, everybody else was crying, and I thought, 'They're all crying for my aunts?'" She found out the Challenger had exploded and all the kids were crying because of that, so it just

added to her sadness for that day and the trauma of that day.

We did not stay in LA [Los Angeles] long. The jobs, it wasn't M.D. Anderson. It wasn't what we were accustomed to. We found that we had no support system, really, to speak of. What I found, I think, most of all, was, "Oh, my God, now I have to come out all over again to all these people," and I clearly still had issues about all of that. So ultimately we decided that wasn't the place for us, and we came back to Houston after less than a year of being there.

Then I was trying to decide what was I going to do? Deb went back to work on the IV team at M.D. Anderson, which is where she had worked before we left. Deb ultimately stayed on that team until retirement and became — she's actually world-renowned, she's done so many studies, written many papers, and lectured all over the world as a part of M.D. Anderson and as a consultant after her retirement.

I didn't know where I wanted to go, and I didn't know what was available. Then I heard about this hospital. I had word that this hospital was going to open. It was going to be a joint effort between M.D. Anderson and AMI, American Medical International, Inc., a private corporation, to open this hospital to treat people with immunological disorders, but [mostly] AIDS.

SCHWARTZENBURG: It was AIDS.

NELSON: Yeah.

I interviewed for the position, for a position. I wanted to see what was available. They wanted to start an infusion-therapy team. I had worked on the IV team briefly, for about six months, at M.D. Anderson, so I had experience, so I got hired to be the IV team there. I started work when it opened.

SCHWARTZENBURG: One, it was way up 45.

NELSON: It was.

SCHWARTZENBURG: Were you aware of the controversy around that?

NELSON: I really don't recall. What? Tell me.

SCHWARTZENBURG: Well, just that it was so far away from the community.

NELSON: Oh, well, yes, that once again everybody was being pushed over to the side. I

don't know. I mean, none of us were that thrilled. We would have been happier for it to be a little more central. I just figured it was the space that was available. I'm clueless.

SCHWARTZENBURG: What were the patients like?

NELSON: The patients were a lot of the same guys that we had known from Anderson.

That being said, I didn't necessarily know all of them, because I had been gone from Anderson now for a while. I guess it was 1984 I left Anderson, and now this was 1986.

Anyway, I was really excited about this job. I was excited about my role. I was thrilled to think about working at a hospital where we were going to be taking care of people with AIDS. I remember, we started out just like this crazy ragtag bunch of people, and all these guys, and the majority were [emphasis] men. We may have had a couple of female patients, but they were few and far between. The majority of our patients were gay young men, and there were a lot of us on staff who were gay, so in some ways that job was, except for why we were having to do it, it was fabulous, because it was such a, I thought — I felt so at home there and so at ease. We all were just so accepting.

Now, there were some AMI staff members who I guess had been at that

hospital when it was whatever, I guess a general hospital before it converted, and some of them were not so thrilled. Yet I felt like they had other options. They could have transferred, so I think maybe most of them were at least open-minded enough to be there.

I wasn't thrilled with some of the nursing practice, especially related to my infusion therapy, my indwelling catheters that I was placing. That was when we had the "magical exploding" [sarcasm] catheters. I was on call for six weeks solid, on call because there was nobody but me. I hadn't thought about that aspect when I took the job. At that point, I was like, "You've got to get me one other person, one other nurse," because at least we can rotate call every other week.

I was having to show up at the hospital all hours because the nurses would push — the catheters could get clotted, and they did on occasion, and the nurses, even though had been taught not to, they would forcibly try to push fluids in, and explode the catheters, blow them up like balloons, and pow. So then of course, you've got a catheter with an air hole. That was just the frustration of the job. The good part was, they did give me another nurse, Mary Sanchez, and Mary and I were the IV team until really close to the end of the whole thing.

What I loved about my role there was, I had a lot of autonomy. Even more than that, I had a very small — it had been an inpatient room that now was being used for the catheter insertions. So these guys would come for their weekly dressing changes, and it was just me and them. They're lying down on the bed, and I'm changing their dressing, and we're just chatting. Sometimes it was just about nothing: movies they had seen, things they had done. Sometimes it was

about fears and thoughts and concerns. It was a very intimate setting, and I felt so happy to have that opportunity to hear them and be there with them. Again, it was that feeling of “this matters.” Now again, we were still seeing people die frequently, and you never knew.

Two of my catheter stories that I remember the most, one guy, his partner was an LVN [licensed vocational nurse]. He took meticulous care of the catheter, and this poor patient, he would get an infection like every other week. It was just tragic. It was just, “Oh, my God, no. It’s infected again. What? Okay,” so we’d have to treat it, and then we’d have to maybe remove it and put another one in.

Then there was this other patient who called his catheter “she.” He referred to her as a she. “Oh, she’s fine. I was in Galveston this week, and I went swimming in the bay. I took the dressing off. She’s fine,” and she was. That was what was crazy. It was just crazy.

SCHWARTZENBURG: She shouldn’t be.

NELSON: She shouldn’t have been, but she was.

Those kinds of things, and again, of course, getting close to some of the patients and going out socially, going to dinner, going to the movies, and then watching them slowly waste away. It was, again, sad and hard work, but fulfilling because of feeling like we were doing something that mattered. We were kind of on the frontlines here. Then we got word this place was going to shut down.

[END OF AUDIO PART 1]

SCHWARTZENBURG: What happened?

NELSON: We heard that funding was — from what I know, and I was not on the inside at all, but my observation and bit of rumor knowledge was AMI thought they

were going to make money hand over fist. “Man, we were going to really rake it in with these.”

Nobody had insurance. Nobody was wealthy. I mean, okay. A few people were, but not the majority.

I think they also were very mistaken in that they thought this was going to fill the hospital inpatient area. No, the majority of these patients remained outpatient. The majority of those inpatient unit rooms became outpatient clinic rooms.

I had some friends, nurses that I worked with at Anderson, and I recruited them to come over, and they worked on the inpatient unit there. I was infusion therapy. Dr. Mansell, everybody, was still working as they had at Anderson with this much —

SCHWARTZENBURG: Clinic.

NELSON: Yeah, clinic sort of orientation.

So AMI saw that they weren't getting rich off these poor, ill people, and I guess they decided that it wasn't worth funding anymore at the level that they had.

SCHWARTZENBURG: But they had made a lot of money at Park Plaza. Do you think the physicians at Park Plaza just admitted more, and maybe the M.D. Anderson physicians were just more clinic-oriented, and so they didn't?

NELSON: I think what was happening there [at Park Plaza] was, there were physicians in private practice who were seeing their patients outpatient in their offices and then admitting them to this hospital [Park Plaza] where they had privileges.

At this hospital [Institute for Immunological Disorders], it really was

following the M.D. Anderson setup where the majority of patients were seen outpatient, and you were only admitted if you absolutely had to be. They were having to fund the whole thing, including the physician office part of this, and I think that's where they had a complete misconception about the way this would all unfold. Perhaps they should have taken a little closer look at the whole M.D. Anderson concept, that model, before they mistakenly thought — because these doctors were using this as their clinic area just like at Anderson. I don't think the inpatient unit ever stayed completely full, and it was only a small floor that was used as inpatient. It never became more than that. Then yes, we began to hear that things weren't working.

I forgot to tell you about the part — Dr. Rios. I remember the day that everything started, they had all these opening ceremonies and all this thing, and then Dr. Rios would do little pep talks for us through the time that we were there. He had this great Hispanic accent, so he said early on, it was either at the opening or soon after, he was saying, “We have all chosen to be here,” but what it sounded like was, “We all have shoes to be here,” or, “We all have shoes to work here.”

This sort of became our little secret rallying cry, not to his face. We certainly didn't mean to be offensive by it, but whenever we'd have a bad day, one of us would say to the other, “Well, we all have shoes to be here,” and we'd look down at our shoes and say, “Yes, we do.” And we did. We all chose to be there. We all chose to work there. It was a great group of people for the most part. The people in the trenches were there because they had “shoes” to work there.

Once we heard that things were closing, everybody started being like,



Jane Nelson, 1990

“Oh, my God,” but it wasn’t like a for-sure thing, but rumors were flying, and then the man who kind of had the vision [for the institute] about this, Dan, he left.

I remember one of the nurses saying, “Well, when the visionary leaves, you know, the dream might be over.”

Then Jesse Jackson, maybe he was running for president, or he was an early potential presidential contender, which is cool, even back in the day, so he came and visited the institute, and we were all starstruck and we all thought, “He’s going to do something.” I don’t know what we thought he was going to do, magically produce a pot of gold or something and we could stay in our jobs, but no, that didn’t happen.

A lot of people didn’t know what they were going to do after the institute.

A lot of patients were very concerned about it.

SCHWARTZENBURG: I’ll bet it was a very sad place.

NELSON: It was that feeling of the sinking ship and nobody was bailing us out. Nobody was literally bailing the sinking ship.

“Now what do we do?”

A little before this all came about, I ended up — I can’t recall how or why, but Dr. Mansell needed another research nurse, and I think I was worn out with the every-other-week call, so I abandoned poor Mary, although another nurse took my job on infusion therapy, and I transferred back to M.D. Anderson on paper,

though I was still physically at the institute, working for Dr. Mansell, doing research on AZT [azidothymidine], so I started doing that.

It wasn't long after that — I can't recall exact time, seems like days, but I know it wasn't that short; it was maybe a few months or maybe a few weeks — that things did fall apart, and we got the final word that yeah, this isn't going to happen. This isn't going to stay. We were so sad because I think most of us still had shoes to work there and wanted to stay, and we couldn't because it was leaving us, much like our patients.

SCHWARTZENBURG: Where did the patients go? Do you know?

NELSON: I think a lot of them had to go out to county hospitals. Now, those who had a cancer could go back to Anderson. Some, who were insured, could go to — some of our physicians went into private practice. There were other physicians seeing patients with AIDS who already were in private practice, so the insured patients could do that. Many had to go to Ben Taub or, if they lived outside Harris County, which I know about from a personal standpoint, had to go to John Sealy down in Galveston. It just was what it was.

During that time that I was working in the AIDS hospital, I sustained a needle stick, so that was a scary thing for me, but nothing, fortunately, ever came of it, and it was really not a huge stick. It just happened while I was suturing a catheter in a patient. He was a jumpy, nervous fellow anyway, and then I poked this needle into my own finger. I tried to remain as calm as possible and just tell him, "Excuse me just for a moment," and I went and washed my hands and put on fresh gloves.

One of the social workers was across the bed from me because she was

standing there. She was staying with him to try to help him be more calm, and I remember her eyes got like saucers, and mine, I'm sure, did too. But no, everything was fine. They tested me for a couple of years, and then all was well. Yet that was something that could and did happen to all of us at various times.

My co-worker Mary was putting a catheter in, and blood just shot all over her face. I don't think it got into any open wounds or anything, but it was — we all still had fears and concerns about our own health, and yet not enough that it certainly would stop us.

SCHWARTZENBURG: Let's talk about your brother, Mark, and the timing of that.

NELSON: The AIDS hospital closed. I went back to work at M.D. Anderson and stayed there until I retired. So Mark, my brother, as a teen, when he was about 16, got high and crashed a motorcycle that he had, and he was paralyzed and couldn't speak and was in the hospital for quite some time in a coma. When he woke, he had to relearn to walk and talk and all of that.

Mark had always been a challenging fellow, but this now added to the challenges of Mark because it was a closed head injury and resulted in a real lack of impulse control and a real lack of ability to control emotion, most particularly anger, so Mark kind of bounced around through life as an adult. If he hadn't had that accident, perhaps he could have kind of settled in and been okay, but he did.

Mark, in the 1980s, this was when I was still at Anderson the first time, I remember I was sitting out at the charge nurse desk in the hallway, and my brother shows up right in front of me, and this is a tall desk. It's chest-high when you're standing, so I see my brother, and I'm like, "Mark, what's up?"

He said, "Oh, man, I got away from the cops."

Mark at this time had decided he was gay. He was living with my parents. Let's see, this is the 1980s. He was in his twenties, and he was making a living by hooking out on the Montrose circuit. He had been picked up by the police because he had gotten into a scuffle with some other guy, and this is so Mark, so he stands there talking to me forever, and I'm like, "Mark, what's up?"

He goes, "I just need some money. I just need some help."

You couldn't bring Mark in, because Mark would not come and stay for more than a short period of time. He would get angry. He'd start stealing. It was unfortunate.

I stood up and walked around the desk, and my brother has no pants on. He's this tall guy, and he's completely without pants. He has underwear, thank goodness, but no pants.

I'm like, "Oh, my God."

He didn't even preface this by saying, "I need some pants."

SCHWARTZENBURG: "I need money."

NELSON: He's standing there talking.

So I took him to my office, and I got him some scrubs, some paper scrubs, and I put him in those, and I was like, "Where are your pants?"

Well, he'd lost the pants when he ran from the cops. That's Mark, always a bit of a problem.

Mark got picked up by a psychotherapist who had a practice in Royal Oak, Michigan, and he was here in Houston on vacation, and John decided he was going to fix Mark, so he took Mark home to Michigan with him. This was Mark's gay phase. I don't know if Mark was kind of like me, a little bit bi, or if Mark

was just looking for some love and some stability. John kept Mark up there for about three and a half years, but in time I guess Mark got to be too much even for John, and so Mark came back to Houston. Then he was kind of in and out of my parents' house and doing whatever he did until around 1990-ish.

At that point, Mark decided to get married to a woman, so he married a mentally challenged woman, and they were sort of like two 10-year-olds having a marriage, but at one level it worked for them for a while, so that lasted for a little while.

Then around 1995-ish, maybe 1994, they split up, and I begin to notice that Mark — Mark was always tall and slim, but I noticed he looked slimmer than ever, and I couldn't help but think back to when he was living — I mean, he was having multiple sexual partners. He was using drugs. I know he used IV drugs. So Mark put himself at risk in a lot of different ways.

I told my mom — she was working for a doctor. She was working in a doctor's office as a receptionist, a gynecologist. I told her, I was like, "Mom," and Mark was staying with them at the time, and I said, "I'm concerned about Mark. I think he needs to be HIV tested."

She did. She had him HIV tested, and yeah, he was positive. Very quickly he developed PCP [pneumocystis pneumonia], so he was hospitalized for the first time. Mark lived with my parents. They live in Montgomery County. They live up just south of Conroe. They moved up there when Mark was a teenager because they were sure that was going to fix him and he was going to be better if they could get him out of Houston. That worked well [sarcasm].

So he had to go down to John Sealy. He couldn't come to Ben Taub. He

was not insured. They would take him for these few years back and forth to John Sealy. He had several bouts of PCP, was hospitalized several times. During that time, I guess Mark was — well, no, he wasn't stable. He would get into fights with my dad, who by



Jane and Mark Nelson, John Sealy Hospital, Galveston, TX.
Winter 1997

now is elderly, and they're getting into these fistfights. It's just absurd. Mark is like a walking skeleton, my dad is an old man with MDS [myelodysplastic syndrome], and this is going on. I remember the last run-in that I had with my brother, this was just like, "Wow, so here we go with even my brother."

And truly I was concerned about my sister, because Wendy had also gotten into drugs and alcohol. She wasn't quite as, well, I don't think in quite the same risk situations as Mark, but she was making really bad choices. In fact, Jennifer, her daughter, was now a young teen and had left and was living with my parents as well, so Jen was going through quite a bit up there with the fighting and the — Jen and I feel almost like we went through the same childhood because she lived with my parents, but my brother by then was causing a lot of hell in that home and was making foolish choices still.

I remember that my brother came here one day and was helping Deb and me do some chores around the house, and it was probably the happiest I had seen

him and the happiest we had been with him. That was nice to have that little, brief memory because not many weeks after that, I got a call from him. He was at the police station downtown here, had gotten picked up for vagrancy, but in fact he had a car, but he had gotten so high he couldn't remember where he had parked it. So we went and got him, and probably shouldn't have, because he was high on drugs and insisted that we drive him all around downtown to find his car. After a couple of minutes of this, we realized he had no clue where his car was.

We brought him back here to the house and called my parents to let them know to come get him because we couldn't keep him here because he was acting out big time, screaming at us. I just said, "Do you want to come get him, or do you want me to take him back to the police or call the police? I don't know what to do with him."

I think by then there was the brain injury, there was drug use, there was AIDS dementia. There were a lot of multifactorial issues going on with my brother. So that was a bad, bad scene.

Soon after that, he got sick again. They took him back down to John Sealy, and we all went and realized this might be it. I was sitting with him in the room, and it was interesting. I don't know. I don't have a religious belief, really, but at that time I guess I had a little more spirituality than I even do now. Maybe I'm too jaded from it all. I remember just having these thoughts while I was sitting there. He was so laboring to breathe, just so much distress, and I remember thinking to my mother who had died, my original mother, "Mom, just come and get him and hold his hand and help him."

Mark said, "No, Janie's mom is in the waiting room. No, Janie's mom is

in the waiting room.”

I said, “Mark, what is it?”

He said, “This lady, I’m telling this lady that your mom is in the waiting room.”

So I don’t know. I don’t know, but it was kind of a — and then I just said, “Well, Mark, I asked my first mother to come and be with you.”

Then he didn’t really say anything more.

Then for some reason, we all thought it was okay to go home that night. The doctor said he probably will be stable. I don’t know why we thought we should come home, but we came home.

Then in the middle of the night they called and said he’s not doing well, so we all rushed back. My dad, I think he just didn’t want to see it. My dad said, “I’ve got to go home.” So they were all here. Everybody was here in our house in Houston. My dad said, “I’ve got to go home and change before I go back.”

I’m like, “Daddy, no.”

“No, I’ve got to go home and change.”

The rest of us pile in our car, and we go down — my mom, my sister, Jennifer, Deb, and I — and my dad isn’t coming and isn’t coming, and they’re keeping Mark on a vent. Finally, they’re just like, “You know, this isn’t working.”

I said, “Mom, they need to extubate him. This isn’t okay.” I said, “I’ll stay with him while they extubate him.”

I did, and he lived for a little few minutes after that. I mean, long enough for everybody to come in and for my grandfather, who was in his nineties, to

show up and start saying, “Squeeze my hand.”

“Granddaddy, no. No, no, no. Just let him be. Let him be.”

We all said our goodbyes, but he died before my dad came. I think Daddy needed it to be that way.

Anyway, my last AIDS person was my brother for a long while because at Anderson I stopped doing direct patient care and got into roles that were one step removed.

SCHWARTZENBURG: More administrative?

NELSON: Yes.

SCHWARTZENBURG: Tell me about the AZT research.

NELSON: It’s interesting. *Dallas Buyers Club*, that movie, I had very mixed feelings watching that movie. I completely felt the concern of the patients. You know, this isn’t happening fast enough. But their belief that the medical community was withholding treatment made me sad. It made me sad. There are still people today who think that the medical community is withholding cancer cures. Again, if that’s the truth, I am the most naïve and gullible person in the world because I don’t believe that’s true. I believe there are too many good people working for an end to all of it, but I don’t think that’s even possible because none of us are going to live forever.

At any rate, the AZT protocols were very tough on the patients, very tough. That’s part of why my brother died when he did. Nowadays there are the cocktail drugs, and there are preventive drugs, and there are things that — not to say that it’s easy. It’s like saying it’s much easier to come out now than it was back then. Well, in some ways that’s true, but in so many ways it is not at all

true. I guess I would say that about treatment for people with AIDS. Those protocols required such stringent, like, wake yourself up every few hours and take this pill all through the day, all through the night.

Everybody was trying to find the answer and find the cure and find something, ddC [zalcitabine], AZT, all those drugs back in those days, but I think people were just trying really hard, really hard to find the answer, and at least my motives were always pure. All we were doing was follow FDA [Food and Drug Administration] requirements, the same that still happens with any drug test. Whether our country has too stringent of requirements, I can't say. I know sometimes there were compassionate IND's [investigational new drug] that were where people could get drugs that were off protocol, but this in the early stages of trying to find treatments for AIDS, I feel like at least at the institute everybody was very sincere in the efforts that were being made.

It was a lot to ask of sick people, people who were so sick, and yet wouldn't anyone, when you know, "Okay. I have to wake up and take this pill that is making me sick as a dog every few hours, but if I don't, I'm dead for sure." God, what a horrible, horrible place to be in.

My brother just couldn't do it. He couldn't comply with the treatment requirements. He had all these pills, but he just couldn't. Who knows? If he had been able to, maybe he would have survived longer. You know, he was a troubled soul. I know a lot of patients, for various reasons, just found it too stringent, found it too imposing. I mean, when you can barely even move, to have to wake up and take pills is a lot, a lot.

SCHWARTZENBURG: In interviewing some long-term survivors, many of them chose

not to take AZT. Do you have thoughts about that?

NELSON: I certainly understand, and yet my brother chose not to, and look where that led for him, although maybe for him, he was already so far along in the process that it wouldn't have made any difference anyway. Again, because the drug itself was so harsh, and so clearly for some people that was the right choice. I don't know. It was such a confusing time as to what was the right path to take, what was the right thing to do, that I'm glad for anyone who survived that time and is still around to talk about it, very glad, because not that many were.



Jane Nelson, 2015

Magic Johnson, there's somebody who's a public figure, but most of the people we knew were the Rock Hudsons, the ones who didn't last long and didn't even know what they had until it was too late, and even then, what do you do?

Ironically, I know someone who just was diagnosed with AIDS a couple of years ago, and he's surviving. We don't stay in touch as we once did. That's not because of that. I just thought, "Wow, still. Of course, still."

I worry about young people now who don't have a clue really about how deadly and horrifying and crazy things were and are even careless in their own lives because they don't — I know treatments and medications are available, but don't put yourself at risk. Don't go there.

Even my grandkids, we had this discussion the other day. I was alone with them for a brief time, and they were talking about their other grandparents, who are rather conservative. I said, “So I guess if one of you said you were gay, that wouldn’t go over very well with your grandparents.”

They said, “Oh, no.”

I said, “Yet I kind of always hoped one of you might be.”

My grandson said, “No, no, but I would come to you and tell you, ‘I’m gay,’ and you’d go, ‘Oh, no, you’re not. That’s my [emphasis] thing,’” which I loved.

But that led to a discussion about AIDS, because I mentioned their Uncle Mark, whom, of course, they never knew. He died two years before Evan was born, my grandson. Payton, my granddaughter, who’s now 14, asked me, “Exactly what is AIDS? Because I’ve heard about it, but I don’t really understand it.”

I thought, “Yikes.” I mean, this is an important thing for you to understand and how to be safe and have safe sex, so we had the whole discussion. I’m sure she must have heard this at school before, but knowing Payton, she probably tuned it out at school [jokingly]. Yet I thought there are a lot of kids her age, maybe older, maybe who don’t get the importance of being safe and taking care of yourself and avoiding risky behaviors even today, even now.

My friend, he was not a young man at his diagnosis recently, and he certainly knew and even remembered and lived through all this time. I don’t know. Even now, one slip or one error in judgment with a sexual partner, and there you are, potentially.

SCHWARTZENBURG: That really is the message. That really is why we remember, why we tell these stories, why this collection is so important.

NELSON: It is. It's a memory of the time. I know I wasn't real specific about a lot of people in this memory, but I remember so many of them, so many of the guys, and little incidents. I just don't ever want my grandchildren to ever have to experience something like we did then, with friends dying and people confused. It was just really a sad time for us all, I think.

I'm glad that advances have been made and some of these people are still working on the forefront. The doctors are still out there doing that work. I'm glad I'm retired.



Jane Nelson and wife, Deb Richardson, 2016

I didn't say, not that it matters [for this oral history], I guess, but the way I suddenly acquired grandchildren was that my sister also died, not of AIDS, thankfully, but she died of a brain bleed because of a heart valve replacement from drug use. There you go again, still risky behaviors causing death.

Jennifer, her daughter, was well an adult by then and had her own children. The kids were little. She wasn't close to her dad and hadn't been, and we began talking, and decided, along with Deb and me, we all three decided that we'd become a legal closer family, and so we adopted her.

Then Deb and I were finally married. When? Three years ago, I guess.

Now, not only is Jen our daughter, but legally we are also hitched after 39 years. Thirty-nine years we were together when we got married on our 39th anniversary. That's a good thing. It's a happy thing.

I wish that my brother could have had a longer, happier life. I wish my sister could have. Who's left of my family are me and my mom [my stepmom who adopted me when I was a child]. She's still around and kicking.

SCHWARTZENBURG: Well, I appreciate your time. Thank you for telling your story.

NELSON: Thanks. I hope it's of some help.

SCHWARTZENBURG: It is.

NELSON: I guess still trying to do something that matters.

[END OF AUDIO PART 2]

[INTERVIEW CONCLUDED]

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