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MN: I guess, your personal experiences are what I would like to know about. I understand that you had polio very early.

JL: I was right about two and a half years old.

MN: So how much do you remember of having polio?

JL: I don’t know that I can remember that much. I know that I have heard stories, so I can’t discern whether it is memory or stories. I think I remember the hospital room that I was in. I think I can remember the cribs that are in that room. I think I can remember one of the nurses, but again I don’t know if its memory or because we’ve talked about this all the years that I have been alive, so I don’t know which it is. Is it somebody telling me so that is why I remember? Or is it what I really do remember?

MN: Based on that memory, what were the hospital rooms like?

JL: The room that I think I remember was a square room, and there were three crib beds in that room. And one of the crib beds had a boy in there. I remember them wanting to take my picture, and I was not very cooperative. I had made kind of like a tent of my crib is what I can picture. And I hid in my tent, because I didn’t want to be photographed. I remember a black nurse caring for me. I don’t remember bad experiences. I don’t remember a whole lot of pain. My first real recollection that I am sure is from memory is when I went to Mary Freebed from
shock therapy on my face. And those are definite memories, when I was a little older. As a child, again, I don’t know if it is memory or people talking to me.

MN: What was the shock therapy for specifically.

JL: Then, in those days, I was a little older, probably five or six when they started having this theory that if they did shock therapy on the paralyzed side of my face it would shock the nerves into growth. So every, I don’t know how often, maybe every month. I remember my mom and I would drive into Grand Rapids, and they would do shock therapy on the left side of my face trying to bring it alive. I could not feel it, they would run this kind of wand over my face, and I could not feel it but if they touched the other side of my face it was definitely shock therapy. It was definitely voltages of shock going through, it was quite painful. But when they touched the left side of my face there was no feeling at all. And that went on for a while. They used me to get other people to put up with the pain and they would use me and say, see this little girl, we touch her and she doesn’t jump and scream. Actually it was kind of deceiving because I couldn’t feel it anyway, so, obviously the people that they were trying to use the shock therapy on were feeling it more than I.

MN: What were all the symptoms you suffered from, do you remember?

JL: After the polio, during the polio, after the illness?

MN: During and after.

JL During the illness, I don’t really remember anything. I am told that I had a fever of 106. I am told that physicians told my parents that my brain would not be functioning after all this, and that they should just be prepared for someone that
was retarded. I don’t remember the fevers, I don’t remember the trip to Grand Rapids. I don’t remember anything like that. I just know what I was told.

MN: What about after?

JL: Growing up, that’s a different story. Again, paralysis, I have two pictures. One before polio, and one after polio. The after polio child is definitely an experienced child. The look in my face showed that I had gone through a lot. I was a very happy child prior to it. All the pictures that were taken of me had smiles in it, and afterwards, there were no smiles. Lots of [pause] self-doubt, as I was growing up. A lot of insecurities. I knew I looked different than everybody else. But I think it helped me grow, and helped me to be the person that I am today. It wasn’t easy. Kids can be awfully cruel. I think I lived a reality of anybody that has a disability. And you just learn to cope with it. In my years now. I use it more than I shy away from it. I have experience now that as a nurse, I am a RN, it gave me an insight into what patients are going through. Stroke patients who deal with paralysis. It really helped, it helped me have more empathy with them.

MN: So growing up, did you feel any kind of, maybe ostracized is the right word—?

JL: Sure, absolutely. And it is not just growing up. It is as an adult even in this day and age. I go out to eat and public, people watch me because I can’t keep my lips closed when I eat. I just don’t chew anything, I swallow everything whole so that I don’t have to chew in public. In my own home I do have to assist in the chewing, I don’t have the strength to chew. The left side of my face is all paralyzed. The effects? I have had several reconstruction surgeries as I was growing up. The first one started when I was sixteen. My lower jaw never grew,
so, I had what they call buckteeth. And it is not a very nice thing to look at a child, a young girl with disfigurement like that. Forty years ago, they didn’t have the wonderful ability of plastic surgery that they do now. Then all they could do was chip away the bone, cut away the teeth and give me a bridge, so that I didn’t have a protrusion on the upper jaw. That was okay. I lived that way till I was about, I would say 26 or 27. And then I had more plastic surgeries with a plastic surgeon in Grand Rapids who shift my face around a little bit, straightened up my face. It was a little crooked. My nose was off center. So he straightened my nose up, gave me a smaller nose. And he gave me a chin. He took part of my rib and put it up on my chin, so that I now I have a chin. About 15 years ago I again had some more plastic surgery. Again, medicine improved. They were able to do a lot more things. As I was getting older, I was starting to get a protrusion again, so I went to see and oral orthodontist and he said that he could do miracles for me so I fell for it, and he did. He did. He really did change my appearance immensely. But I went through about four months of hell to get there. What they did was, they did a Man Dibular and Maxillary Osteotomy. What that means is they moved my top jaw back into my face and they moved my lower jaw forward, so that it would give me a better profile in chewing and stuff like that. But they did not know that the bones in my face were very, very soft. They told me it would be a two-week recovery, and it ended up to be a four month recovery. I was wired shut. My lower jaw was wired to my eye sockets for three months. To let it heal. So it was an experience. I am glad I did go through it. The ultimate outcome was quite a change. So I have had several faces that I have had to get used to dealing with
over the years. I think I am done now, I don’t think I will try any more!

[Laughter] So I think I am done.

MN: What about growing up? Do you feel you were treated differently [JL nods] than say your brothers or—

JL: My brothers didn’t have any outward appearance of polio. I had bulbar polio and that attacks the neck and the face, the nerve endings of the face. They ended up having spinal polio, which can be very devastating, but they had a milder case. So they are not really restricted by anything they do. My older brother (they nicely caught polio from me thank you very much) [laughter]. My older brother does have one shorter leg, it is about three quarters of an inch shorter, but that never stopped anything he wanted to do. He was in the navy and he had done several stints in the Navy, so, to look at them, you would not see an outward appearance of anything that they went through.

MN: Do you think, was there any, I guess, I am trying to think of how to phrase my question. In public, in a community of people, did just the fact of having had polio that caused problems or was it more—

JL: It was more appearance. Not, the fact that we went through polio, I think my family had a lot of good support and they are proud people and they did not want handouts. The Polio Foundation was willing and ready to help them but my parents are very proud people and they did not, to my knowledge, accept any help from the foundation. We did do a paper drive to try and raise money for the polio foundation. I don’t know if my mom told you about the hard times because neighbors thought that we were getting help from the Polio Foundation and they
would make comments about being helped, but indeed, I do not know of any help that they gave us outside of psychological support and being there with information. As far as having polio, we were not ostracized from the neighborhood or friends for having it, they didn’t think we were contagious or anything like that. It was more appearance to strangers, people you didn’t grow up with, new kids in school. I had a group of friends all the way through grade school, started out young, neighborhood kids. They were used to me and it was no big deal, but as I grew and had to communicate with other people and be around other people, that is when it become more difficult.

MN: As far the community goes, do you know, I know that you were really young, do you know if polio was a big topic to conversation in town?

JL: Everybody was afraid of polio. Definitely. One of my boyfriends when I was younger had polio. He was from Allegan, MI. Everybody was aware of polio and real fearful of that. And the vaccines came out just a little too late for me. And I remember my mother hauling me down to the school, because I was going to do this sugar cube with polio and I was thinking was a live virus. I was scared, I was really scared to take that little cube of ice, or that cube of sugar, because I thought for sure that I was going to get polio all over again. So yeah, everybody was very alert to polio. They were afraid of polio, they had lost a lot of people to that disease.

MN: What was Holland like during that time as you were growing up as people feared, what was the community like?
JL: Close knit. Everybody, you had neighborhood communities. What you are now, you are not a neighborhood community anymore. Neighbors helped neighbors. If somebody had a problem, your neighbors came forward and brought your food and were supportive, they were close and you knew everybody in the area. Of course, I grew up totally on 18th street, I never left 18th street. I lived between Harrison and Columbia, and then I moved between Van Raalte and Columbia, and then I moved one street over between Washington and Van Raalte. So there was not a whole shift of people we kind of knew each other. We had community churches, people didn’t drive ten miles to church, they walked to church. We went to Bethel Church and usually the whole area would go to that church. So it was quite a close knit community.

MN: You may not have experienced this, were there any difficulties in town with accessibility of places, as a result of polio, or disability from polio?

JL: I would not know. In those days you didn’t have wheelchair accessibility. People picked you up and brought you into church or whatever was needed. There was not this push to have everything, like now a days, the rights to be able to go places. No, you just lived, you didn’t worry about that, if you needed help, people helped you. They took your wheelchair and carried you to wherever you needed to go. It was more of a need, a reliability, you needed to rely on your neighbor, now a days, everybody wants to be self-reliant and independent, and don’t want to ask for help as in those days. People were right and willing to help you.

MN: Where did you go to school?
JL: I started out at Van Raalte. It was a grade school. Just a block and a half, to two blocks away from me so I could walk to school. I went from Kindergarten to Sixth grade there. Then the big change. At seventh grade I had to go up to Jefferson School, which was on 32nd street. That was scary. That, because that didn’t have just the kids I went to school with at Van Raalte. It had other schools. They all mingled into that. That was a scary thing for me to go to Jefferson School. After that I went to EE South, a Junior High School down on 16th street. By that time the shock was over and I kind of found my place. The new high school, Holland High School opened up in my Junior year and around Christmas time we moved over there. During high school, not many of my classmates knew I was there. I went to class, then I came home. I didn’t socialize, I didn’t get involved in anything. I was kind of by myself. By my own choosing. I have had people say to me that I needed to get out of my shell and, classmates would tell me that. I couldn’t do it. I just couldn’t do it.

MN: More comfortable.

JL: I was comfortable by myself. So I stayed by myself.

MN: Did you ever meet anyone along the way who also had been through polio?

JL: Not anybody that was visible. Until I got into high school, and we had an exchange student from Germany, and she had had polio, and it affected her leg. Now I didn’t ever talk with her. She was kind of in the clique of the popular kids so I never even approached her, never tried to talk with her.

MN: Did you ever participate in any kind of fundraising or awareness activities in town?
JL: No outside of when we were little children and had the paper drive, the polio drive. Mother went out every year, faithful, in any kind of weather. I would go with her, but I never really participated.

MN: What do you think the effect of polio was, not just on yourself, but on the people around you together. How would you describe them, the effects—?

JL: As I was growing up?

MN: As you were growing up.

JL: I found out just recently. They were very hurt by what I was having to go though. They wanted everything right and to protect me, and yet not protect me. I was not coddled, they would encourage me to go do things. I just couldn’t force myself to go out and socialize. It was very difficult on them watching me struggle to find out who I am. As far as friends and acquaintances. I cannot remember ever discussing anything like this with them. I think they just accepted who I was for what I was, and maybe they knew my history from their parents, our parents kind of all, were acquaintances at church and school meetings. So other parents would have known what our family went through. I never had to explain anything with that clique of people. In that day and age the ones that didn’t know me would avoid me or shy away from me. I have since learned that if you don’t reach out to people they are not going to reach out to you. So I never did to make friends when I was in school. I just never did.

MN: What other ways do you think polio affected your, developing your identity?

JL: Well, that was the total focus point on who I was. I don’t think I overcame that person until I got into nursing, and that was purely by accident. It was in a
swimming accident and almost drowned. My youngest brother (he is older than me) owned a cottage on Newaygo River. My brother and I were fishing in a small dingy when some girls in a canoe that tipped over and my brother said “lets go help them.” I was 22 years old, a fairly good swimmer. So my brother jumped out of the dingy, and I, a girl, had to get rid of my watch, rings, and glasses and stuff like that, and I jumped off. As I jumped, my father was the only weight in the back of the boat. So when I jumped off the dingy, the boat swung this way, I did a belly flop. I now know why people drown. I came very close. It knocked all the air right out of my system. Being a strong swimmer, I couldn’t swim. I weighed 10,000 pounds. I struggled and I went down twice and on the way down the second time I saw my mothers face in front of me telling me “do not go down the third time because you will not come up.” My dad could not get the anchor up from the dingy, he could see what was happening. With all the strength that I could, I managed to get to a point in the muck where I could push myself up out of the water, from the floor of the river. Well, a couple of days later my lung collapsed and I ended up in the hospital. I was in the hospital for a week while they waited for my lung to heal and re-expand. I did not appreciate the nurses who were caring for the elderly patients in my room. They would yell at her because she was incontinent of urine. They would not answer her call light when she put it on, so that’s when my nursing career started. The elderly patient, I’ve since forgotten her name, would just tell me when she had to go to the bathroom. I would hop out of bed, and get her into the bathroom. I would first check the hallway, make sure there was no one in the hallway that would catch me. I would
hop over to her bed, haul her to the bathroom and tell her just to yell when she was ready. Now I think of that and I think, oh my goodness, you could have dropped her. They were probably keeping track of her output and were probably wondering why she was not urinating at all. But that was the start of my nursing career.

MN: So where did you go from there?

JL: Well, I was a horrible student in high school. I truly believe that I passed classes from grade school all the way to high school, because people felt sorry for me. They would just pass me along on C minuses, Ds, I would squeak through. I was never held back. I absolutely hated school. So how are you going to get into nursing? They are not going to take someone who is a C, C-, D student, they are not going to take you. I did find that Pine Rest School of Nursing would accept me as a student if I proved to them that I was sincere. So I took a course at Hope College, it was child psychology. I got an A- in it. I brought my A- over to Pine rest and said okay, and they agreed to take me in school. I cannot tell you that it was easy. School was very very difficult for me. I never learned the basics of English. I was not a learned person, so to pass that course was quite a struggle. I give full credit to my teachers because they would tutor me. They for some reason felt like I was worth it, and they would spend nights tutoring me to get me through. We had to make up for everything I didn’t learn in high school. But they got me through the school. I was a LPN for 23 years. I loved nursing, I loved being an LPN, it gave me a lot of confidence and it was really what helped build who I am now. But then I got old and my body wore out. LPN work is heavy. We
did not have techs then, so I was the one who did all the care. And I truly did not
take good care of my body. I did things that I should not have done alone. I would
turn people alone, and I wore my body out. My present husband, bless his heart,
he pushed and pushed and pushed for me to go back to school for my Associates
Degree in Nursing. It was something that I never wanted. I never wanted to be an
RN. I did not want that responsibility. I did not want the hassles. I wanted patient
care and to me RNs were nothing but troubleshooters and paper pushers. I didn’t
want to give up nursing, and I didn’t want to give up hospital nursing, that was
my first love. I went back to school, and I did get my RN. I have worked as a RN
for about ten years on 5 West. I was always challenged by new things. If you’re a
nurse you have to like change, you have to be challenged by change. About two
years ago, the manager position was offered to me and I took it. Never in a
million years if you talked to me when I was 18 years old would I have thought I
would be doing what I am doing right now. I did not have the confidence to do it.
It was everything along the way that got me to this point. I really truly believe it.

MN: Taking a step back, do you know how you contracted polio?

JL: Yup, sure, I do. A neighbor child who was a carrier of polio. A carrier would have
a mild temperature, but you would not have any severe symptoms of polio. [End
Tape 1 Side A] We were playing together, and she was an older girl. She had a
tricycle. I was two and a half years old. She thought it would be fun for me to ride
the tricycle, as I thought it would be fun. She had me on the tricycle and was
pushing me down a little sidewalk. She was pushing me down, she was holding
onto me, then she let me go. So she let me go and I was steering the bike and we
were doing just fine except I could not reach the petals to stop. So I went over the step at the end of the walkway. She picked me up and I think at that moment is when I contracted the polio. I had open cuts on my face. She held me close. Probably breathed in my face and we think that is how I got the polio. Then I passed it along to my brothers. My mother had a drinking glass that she used for me only, and she kept it way in the back of the cupboard. My brother reached for the one hidden in the corner and used that for a water glass. They think that is how I passed it to my brothers. That is all speculation. The neighbors refused to have their child tested, so that is also just speculation. We may have gotten it a different way. But that is how the family doctor and my family think that we got polio.

MN: How do you think polio affected your attitudes towards work and school, and social occasions?

JL: Social occasions. I don’t do social occasions. Even to this day, I am not a socialite. I don’t like being around strange people. I have never learned the art of conversation. Get me in my element, and we will get along just fine. I can talk for hours. But get me out in a social element—I feel uncomfortable. The Jan Souter of two-and-a-half years old is still here. Lacks confidence, is very insecure, is uncomfortable out in public because she can spot people staring at her a mile away. There is still that in me, that is something that I still have had to fight always. I do what I have to do, but I have to talk myself into it. So it does effect me, even to this day and age.
MN: Did your family take any precautions in—because you just talked about how your Mom had the one glass for you—were there any other kinds of precautions that were taken to avoid the spread of polio?

JL: That I don’t know. I have no idea. I know once I was discharged from the hospital, all my toys got burned and all my clothing were burned. That included all my bedding and clothing also. So, I know everything was burned. I only have one toy left from when I was a child and it was a little kitten that they did allow me to keep. And I still have it. But everything else was burned.

MN: When you were hospitalized, your Mom said she had gone to visit, how did that work out? How often was your family allowed to visit?

JL: I think they could visit any time, I don’t think there were any restrictions. The restriction was we lived in Holland and I was in Grand Rapids. I believe my parents came up every day to see me. My father had to work, and I think he needed a car to get to work. So there were some restrictions that way. I don’t remember other people driving my parents up. I don’t really remember any of the visitations. I am sure they were there.

MN: Where did your dad work at the time?

JL: I can’t remember, he’d have to tell you. He had several jobs in Holland, Holland Hitch, and he worked at the pickle factory and the furnace company too.

MN: What about treatments, do you remember the treatments or know what they were?

JL: I know my parents said that they had to suction me to get a lot of mucus out of my lungs and I had a trac, a traciostomy. And my parents said that I took care of that. I did my own suctioning. If I felt some stuff in my lung, I would turn the suction
machine on and I would suction myself. It was pretty remarkable at two and a half years old. I don’t remember that, that’s just stories that they had told me. After I came home, the traciaostomy was allowed to close off. I wasn’t, I don’t remember any specific treatments except going back for shock therapy. I remember doing exercises. In the big bathroom upstairs, at home on 18th street, my mother would make us exercise every morning. They were exercises built for my brothers, which she made me to the exercises too. I remember them trying desperately hard to get the strength back in that side of my face. I remember certain facial exercises that they would get me to try to do, and I hated, to watch myself in the mirror. I wouldn’t do them because I would have to see what was looking back at me in the mirror. I remember that. I never did my exercises.

MN: Where did you find support, emotionally, going through all this, who did you—?

JL: You see, that is this day in age thinking. That day in age thinking, you survived. You did what you had to do. Now everybody has to have a support group. We didn’t have that in that day in age. You know, everybody has something happen to them. Then you just lived, and were thankful for what you had. Your family were the support people around you. They were your protection, but there was no such thing as talk groups and support groups and call this person because you had to de-escalate the situation. You didn’t have that in those days. You just survived. You lived and you were thankful that you had what you had. So there wasn’t any real support per se outside of the family.

MN: Going back to the nursing, what aspects of nursing affected your identity. What was it about being a nurse that helped you develop into Jan?
JL: Well, simply the fact that, I guess I showed my teachers up didn’t I? They told me that I would never amount to anything. Well, because I never applied myself in school. They told my parents that I didn’t have the intellect to go to college. That I should just be satisfied that I made it through high school and then I would be working in a factory for the rest of my life. Just for the pure satisfaction of showing them that, well this one you guessed wrong on. I feel important as a nurse. I like making people feel good. I like making people smile when they don’t feel good. It makes me feel important. It makes me feel like; I survived polio to be something. They had told my parents that I’d one in a million chances to survive. It always felt like I had to do something special and I did.

MN: You did something, that’s for sure. [Pause] I guess you have answered a lot of my questions, I have just a few more that I want to ask. Then I would like to ask you if there is anything I might have missed, I might be curious about. The first one is, the relationships now, with family and finding your husband, how did polio effect those kinds of relationships. Did it at all?

JL: You know, it didn’t. I’ve been married three times. Growing up in my neighborhood and church, we always had maiden ladies. I always visualized myself as being an one. Once I got out of that and really started out in the world, I guess I found out that there were a lot of other people who had other problems, and not many people went through life without having something happen to them. Something that would make them grow, make or break them. After high school I did have friends, I dated and had boyfriends. However I never had that in grade school or high school so it was really different for me. My husband right now is
my best friend. My first husband died in a motorcycle accident. He only had one kidney and in that accident that kidney ruptured so, eventually he had a kidney transplant from his mother but it didn’t work and eventually he died. My second husband was on the rebound, I felt flattered. That didn’t last. We were married for a couple years. My husband now, we have been married for over 20 years. He is my mainstay. He is what helps me be the best that I can be. He stood by me through that last surgery. He has really been wonderful. He got me through RN school. All my temper tantrums and all my yelling and screaming [laughter] and cussing, he helped me through it.

MN: My last question, are you experiencing any of the effects of Post-Polio?

JL: I have symptoms, I don’t know that I would call it Post-Polio syndrome. Maybe it is. My throat, I am having more and more difficulty swallowing. I will swallow and it won’t go down, and it will sit in my throat and I will literally have to keep control of the situation. I purposefully really pay attention when I eat, because it would be very easy for me to choke to death. I don’t know if they want to call that Post-Polio Syndrome, [sighs] maybe it is. Again, I come from the school that it is what it is. Is it normal aging process? Is it a normal, yeah I am tired all the time, but I am 57 years old. Is it just a normal aging process? Everyone wants to name it something. I just think that it is what it is, I don’t have to have a name for it. I did attend a couple of Post-Polio Syndrome meetings out of Grand Rapids. I thought thanks but no thanks. All they did was talk about the woe is me. I have moved on from that. If I have side effects from the polio, it is what it is. I will deal with it, I just don’t want to have to label it. Polio is done and over. I have moved
on. Maybe I have, maybe I don’t. I don’t know, [laughs] I am not ready to call it that though.

MN: Finally, is there anything that should be known that I might not have asked you that has been a large part of your experience?

JL: Really not. I think we talked about most of this. It was a driving force of who I am and what I have done, and my struggles in life. Again, everyone has different struggles that are not visible. Okay, you can see mine. They are right out there in your face. I have learned to deal with it. It used to embarrass me, a lot. I used to think it was my fault. It is not my fault, it is something I lived through. Something I’ll have to deal with. And I don’t know what other people have to deal with. Maybe they are living a hell of depression that I don’t know about. Everybody has to deal with something in this world to help them be who they are. This is mine.

MN: Thank you Jan.

JL: You are welcome.