The Unlikely Ballerina

Chapter 1

I crossed the stage at the Leid Center at the University of Kansas, shook hands with the Chair of the Department of Special Education, and then turned around facing the audience to be “hooded.”  Dr. Tom Skrtic draped a heavy sash of bright blue and crimson velvet and black satin around my neck, pulled tightly in front and cascading down my back like a backwards scarf.

I searched the audience for Mom, Dad, Sister, and best friend Heidi, giving them a huge smile.  Just then, Mom leaned to Sister and whispered, teary-eyed, “And all we ever wanted was for her to be able to hold her head up.”

I held my head high the day I became “Dr. Lance.”  It was the culmination of seven years of hard work and achievement of a dream, my dream.  Thirty years earlier, my parents’ dreams for me were much simpler than earning a Ph.D.

\*\*\*

  I was an unexpected addition to my family. My parents thought that they could not have more children because my Dad had the mumps and they went “down there,” so his doctor considered it a natural vasectomy. My sister was 17 and not really thrilled to have a pregnant mother chaperone her senior year activities. My brother was 15 and bit more enthused, planning fishing trips and baseball lessons with his new baby brother. He later told Mom that he loved me anyway despite my being a girl. My parents were surprised, but had considered having more children before the mumps, so they just settled into the idea. My mother was 38, and my father 43.

My mother thought she had the flu initially and was sick those first few months. Nothing differed from her previous two pregnancies. At eight months, she could not see her toes for the baby bulge jutting out from her thin frame.

On October 29, 1968, she had a doctor’s appointment at which everything seemed fine. Though he thought she had several more days to go, but later that day, she went into labor.

As I was about to be born, the doctor discovered that I was in breach position—feet first, and the doctor used forceps to turn me around head first.  Back then, the technology used to monitor fetal status was not available.

When I was born, the umbilical cord was wrapped around my neck and tied in knots, cutting off the oxygen. It was not clear whether the tangled cord resulted before as I moved in the womb, when I was turned, or if some combination led to the result. I was not breathing, and the nurses had to blow air into my lungs through an intubation tube. My mother estimated that I was without oxygen for several minutes, but I have no specific details.

In the days following, the doctors suggested that brain damage may have occurred, but that the extent was not determinable yet. I asked Mom many times over the years how she and Dad felt at this point, facing the possibility of raising a child with a disability. “Were you scared, angry, or what?”

She said they were afraid that I would die, but that the long-term implications did not occur to them. “You were our baby, and we knew we would do whatever we had to do for you,” she explained.

The doctor and nurses came in and told Dad that Mom could go home, but that they wanted me to stay a few days for observation.

“You might as well keep both of them. Jean won‘t leave that baby,” he told them. He was right. They may have left me physically two years apart on May 23, 2003 and May 27, 2005, but neither Mom nor Dad has really left me.

\*\*\*

Wichita was the nearest large city to the small town of Neodesha. My parents took me to several doctors there, looking for an assessment of my condition and some kind of prognoses. The diagnosis was cerebral palsy, but my parents did not know what that meant. Most of the doctors were less than encouraging, emphasizing all the things I would never do: “She’ll never walk.” “She’ll never talk.” “She’ll never write her name.”

One of these so-called experts, ironically named Dr. Lance, said, “She’s too alert to be retarded. Her eyes are too bright.” My parents’ opinion of my ability matched that of this lone dissenter. They shrugged off the others’ expert opinions.

As for how they should help me with my obviously delayed motor skills and other developmental delays, none had any suggestions. Most advised my parents to put me in an institution and forget me. One was a bit less harsh: “Take her home and love her because that’s all you’ll get to do.”

Mom and dad opted to take me home and love me, alright. But placing limitations on what I could do never entered their minds. Having raised two children already, they decided to just do as they had done with Sister and Bub, adapting for what I couldn’t do as needed.

I did not crawl as an infant because my legs were trapped in braces that did not allow me to bend. Instead, I rolled where I wanted to go. I also had a regular infant’s walker (The kind they outlaw now for notoriously tipping over.) in which I scooted around the house.

When I was nine months old, Dad had to go to Texas for six months to work at another refinery. One night on his way home to our temporary apartment, he bought me a tiny wooden rocking chair. After dinner, he sat me in the rocker, and I sat for several minutes rocking and smiling. Dad was bent on one knee about two feet way, taking pictures, “Kodak Dad” in action. All of a sudden, I stood up out of the chair, stood on my own for a minute, took three wobbly steps and fell into Dad’s arms. Dad could not sleep that night. “She’s gonna walk. I just know it!” He told Mom. The next day, he put me in the rocker again, stepped back, and waited. Nothing. I rocked and rocked, but never attempted to stand or take a step. I think he gave up trying after a few weeks. He was right. I would walk, but it was six years later.

Chapter Two

When I was 18 months old, the refinery in Neodesha closed, and he had to choose to be transferred to Texas or Missouri. Most people from Neodesha moved to Texas, but Dad and Uncle Earl decided to relocate to the Sugar Creek, Missouri refinery. My parents bought a house in Buckner, Missouri, a small town about 20 minutes from Dad’s work. They were trying to give me the small town upbringing that my siblings had enjoyed.

Since Buckner was a distant suburb of Kansas City, a fresh set of doctors and other experts were available to advise my parents. Of course, they weren’t any more encouraging than the professionals in Wichita had been. In fact, one gave me an EEG and told my mother that he was absolutely certain I had severe mental retardation. So much for larger towns having open minds.

My mother was encouraged to enroll me in a therapeutic program as soon as possible. The first program I attended was in an institution for children with disabilities in a town close by. It was primarily a residential program. Children stayed there permanently and, if they were lucky, their families visited occasionally. They attempted to convince my parents that this would be the best arrangement for me as well, but, of course, they rejected this notion.

Mom drove me every day to receive speech, physical, and occupational therapy. I hated being pushed to move in ways my body did not want to. I hated trying to walk between two parallel bars with heavy braces on my legs.

Most of all, I hated the other children, many of whom had severe behavioral problems. One boy clobbered me over the head with a toy broom at playtime. He hit me so hard that the bristles flew out, cascading to the floor. In my panicked state, I thought those straw-colored bristles were patches of my blonde hair falling out. The teacher did not stop him until I screamed for my life.

Once my mom allowed me to stay longer than my usual time because they were going to show a movie. This meant that I had to take a nap on site. For naps, children were placed in cribs with netting over the top, so they couldn’t climb or fall out. I felt like a caged animal, looking up and seeing that net entrapping me. I screamed until someone came and lifted me out.

Later, as I was walking on my knees playing, a large older African American girl named Dee Dee jumped on my back and tried to choke me. Perhaps that cage-like crib wasn’t so bad after all.

On another occasion, my mother came to pick me up and found me sitting in the corner facing the wall.

“What did she do?” She asked the teachers.

“She spilled her juice,” one answered.

“How did that happen? Her cup has handles and a lid.” Mom asked, starting to boil with anger.

“Well, we wanted her to use this cup today,” the teacher explained, showing my mom a tumbler made of slick plastic.

“That’s ridiculous! She can’t hold a cup like this. It’s too slick. It probably slid right out of her hands!” Mom replied.

That particular day had been my day to bring treats for the class. Mom snatched up the cookies, hoisted me on her hip, and marched out of the room.

My sister got a job at this facility on her summer home from college. I rode with her to work. I kicked her dashboard with my braced legs the entire way because I didn’t want to go.

After two years, my parents moved me to a preschool for children with disabilities at a hospital in downtown Kansas City. My mother had been driving since she was 12 or 13, but she had lived in a town of less than 7,000 people, so driving in the city was a drastic change for her.

On the first drive at the new preschool, she got lost in an area of town that my mother describe not-so-politically-correctly as having “no white faces to be seen.” After driving around and getting nowhere but more confused, a man pulled up beside our car and rolled down his window. Mom nervously rolled hers halfway down. “Where are you going?” He asked. My mother told him. He said he knew where the hospital was, and if she would follow him, he would lead us there.

Every day for five years, my mother drove me to this preschool for “crippled” children. From our small town outside the suburbs into downtown Kansas City, the trip took an hour each way. I attended five days a week, 11 months a year. Heading out of Buckner on 24 highway, there wasn’t much to look at, mostly fields divided by clumps of trees and an occasional farm house, nothing that would hold the attention of a three to seven-year-old. I rocked the baby doll I brought along or daydreamed while listening to the radio, hoping to hear “I Don’t Like Spiders and Snakes,” “Put the Lime in the Cocoanut,” or some other catchy 70’s tune.

As the terrain became more populated from Independence into Kansas City, we passed people along the way driving to work. One day, I would have my own car and be driving to work at the fire station or the hospital, since I intended to be a firefighter or doctor. Even at that age, I had an inkling that it might be hard for me to hold a fire hose or stand at the operating table with my crutches, but Dad would help me figure out way to do those things, like he did everything else.    Besides, I probably wouldn’t need the crutches by then anyway. I knew the doctors and therapists said I would never walk without them. I heard them tell Mom and Dad. But I had physical therapy every day and practiced walking each night at home. Someday, I would prove them wrong. Walking was the key to everything.

Each night when I got home, I sat in my yellow bean bag chair, watching Sesame Street, Mister Rodgers, and The Electric Company while Mom fixed supper. When supper was ready, I crawled to the couch, pushed on the cushions, and pulled myself to my feet. I walked as many steps as I could without losing my balance, then dropped to my knees and walked that way to the dining room.

I hardly used my crutches at home. The entire ordeal of using them was slow and laborious. I had to pick up the crutch on one arm, move it forward, put in down, “clink,” then pick up the one on the other arm, swing it forward, put it down on the floor ahead, “clink”. Then I had to push down, steady myself, take one step and then other. All this just to propel myself a few inches. On my knees, I zoomed across the floor, grass, linoleum, (sometimes even concrete—the skin on my knees quickly grew tough as rhino skin), like a squirrel skamping between trees.

Passing through the suburbs closer to downtown, we passed all types of businesses: office supply companies, used car lots, grocery stores, furniture stores, car washes, restaurants, and bars. These were the places grownups went. Someday, I would go shopping for food for my children and furniture for my house, in which I would live with a husband who looked like Dr. Marcus Welby.

When we passed schools, I wondered why I couldn’t just go to one of those and swing with the other kids. Instead, I had to go to therapy, where an occupational therapist made me string beads, speech therapist made me repeat words with “th” and “s” over and over, and a physical therapist made me walk up and down three flights in the lonely, echoing stairwell of the hospital.

There were other kids with whom I could play, when not in therapy, but I wasn’t interested. Most of them smelled either from bad hygiene or near-full colostomy bags hanging from their navels. Many had physical disabilities worse than mine. One girl could barely move her limbs at all. Most used crutches, and a few used wheelchairs. Although “mental retardation” was not in my young vocabulary, I knew I was different from these kids and didn’t like being around them at all.

Mom was once asked to observe me through a two-way mirror at playtime. The teachers pointed out that all the children were playing with each other in the middle of the room, except me. I played off to the side by myself. I know I was a snob for not liking those kids. However, by this time, both my sister and brother had moved out, so I was the only child at home and used to playing by myself.

There were I few things I enjoyed about this preschool. Occasionally, they would set up empty boxes and cans of food as if it was a grocery store. We had small shopping carts which to place our purchases, and there was a checkout counter with a cash register with bells and a drawer that slid out like a real one. I also got to ride a gigantic blue tricycle down the corridors of the hospital, and even got to ride it into the elevator and ride on other floors. If I saw a parent of one of the kids I knew or my favorite volunteer who ran the book cart, I would stop and talk, which did not make my physical therapist very happy.

Each preschool day was spent in hours of occupational, physical, and speech therapies, all in an effort to “fix” me, or at least make me as "normal" as possible. The therapists’ attempts to have me put my tongue behind my teeth to make a perfect “t” sound or scoop food to my mouth without spilling it sent the message that I was not enough as I was. The more I could do things in a typical fashion, I learned, the better my life would be and the more acceptable I would be to others.

Every day but Tuesday, (it was closed on Tuesdays) halfway home we stopped at the Starlite Drive-In for a Dr. Pepper and a vanilla ice cream cone. Mom drove with her left hand and held the cone in her right so I could eat it. The Dr. Pepper rested cold between my braced legs. Periodically, I bent down, attacked the straw, gulps of sweet liquid soothing my parched mouth and relieving another tormenting day of therapy.