

CHAPTER ONE

Buffalo, Wings, and a Prayer

It was a warm day on September 12, 1956. My mom was relaxing on the front porch, reading, when a car lost control, going too fast around the corner. The car hit the maple tree on our lawn, smashed into the front porch, and threw Mom into the air. She landed on the front lawn, bleeding and in pain. Our neighbor had seen the whole thing from her bay window. She was horrified, knowing that Mom was six months pregnant with me.

In 1956, my parents, Jack and Olga Jewell, had been married for 12 years and had two sons, David and Fred. Mom and Dad came from large families, and when they found out my mother was expecting another child, the whole family was excited. My brothers were hoping for another brother, but Mom knew instinctively that the next child would be a girl. Dad was employed by DuPont in Cheektowaga, New York, where they lived, and worked hard to put food on the table. He was a little worried about finances, but Mom had tremendous faith in God and believed that where there's a will, there's a way. She had no idea that this would be no ordinary pregnancy.

The story of my birth has been told by family members over and over again, and, to be honest, I have become bored with the retelling of it. Not that it was a boring event in itself, only that I have told it so many times that I sound like a broken record. (For those of you who are too young to know what a broken record sounds like, consider that a small blessing.)

My mother was rushed to the Sisters Hospital in Buffalo, where doctors frantically tried to save her life. She was hemorrhaging, and my parents were sadly informed that Mom had lost her baby. Mom was screaming that they were wrong — she knew that I was alive even though the doctors didn't. They explained to her that there was no indication of a heartbeat, and that they would have to do a Caesarean section. "We must remove the baby in order to save your own life at this point."

Mom had lost a lot of blood and suffered great trauma. They explained to my dad that it could be a very long night, as they had to stabilize my mom before they could perform surgery to remove me. My dad's sister, my Aunt Gerry, was in the waiting room with him, and she reassured him that it wasn't over yet — she told him not to give up. The following morning, after a tremendous effort in stabilizing Mom, the doctors were finally ready to perform surgery. However, the only thing that ended up being aborted was the surgery itself. In the process of prepping for surgery, a tiny miracle was born! On the morning of September 13 at 8:34 a.m., I came into the world with a faint heartbeat, weighing just less than three pounds.

Mom was crying, saying through her tears, "I told you she was alive!" Doctors immediately informed Dad that his wife was going to make it, and that he was the father of a baby girl. He hugged Aunt Gerry, realizing that she had been right. I was placed in an incubator, going from a womb without a view to a room with nothing but windows! My parents couldn't think of a name for me, so for the time being, I was only known as "Precious Jewell." In 1956 babies that tiny rarely lived, so the moniker was fitting and soon caught on with everyone. "Precious Jewell in the Glass Case" made the morning paper, announcing that at that time, I was the tiniest baby who survived at that hospital. That was my very first press release.

When most babies come into the world, they find the reassuring comfort of being held in their mother's arms, being fed and cared for. I always wondered what it must have felt like for me living within a heated glass enclosure for the first three months of my life. I have seen pictures of me inside the incubator with one leg propped up on the thermometer. Perhaps I was content; after all, what did I have to compare it to? It was all I knew.

One morning at 4 a.m. my parents were awakened by the shrill ring of the phone. They immediately went into a panic, knowing intuitively that something was wrong, and expected the worst. Somehow I had managed to get pneumonia, and I was not expected to survive the night. A nurse told my parents it was imperative that I be baptized immediately. "We have contacted the parish priest," she said, "and he will be waiting for your arrival." Mom notified my godparents, Aunt Gerry and Uncle Russell, so they could be present for my baptism. Soon everyone was gathered around me, praying for my life but knowing that I might not live to see daybreak.

I obviously lived but was unable to keep any formula down until a doctor decided to give me some mashed banana, mainly for the potassium and weight gain. It could have been a combination of everything that gave

me the strength needed to survive: between the Jewish doctor who had donated his blood for my transfusion, the Hindu nurse who watched over me, and the Catholic priest who performed my baptism, it seemed I had many faiths rooting for me! I was finally named Geraldine Ann Jewell, but “Precious Jewell” remained on my incubator. Aunt Gerry always thought I was named after her, but Mom had named me after Saint Gerard, the sacred saint of life, because I fought for my life coming into the world. “Geraldine” was as close to “Gerard” as Mom could get without it sounding butch. Aunt Gerry couldn’t have been more pleased that I was named after her, and my parents were not about to spoil that pleasure for her. My name was always spelled Gerry until I personally changed the spelling in the ninth grade to Geri.

At three months, I finally weighed in at seven pounds, and my parents were notified. “Come get her quickly, before she loses any weight!” When my parents brought me home, it was a huge celebration. I was the size of a doll, and my brothers were amazed that they could hold me with one hand! Our German shepherd, Kim, intuitively took her post as my protector, standing guard over the bassinet and watching me intently. This made Dad nervous.

“Get Kim away from the baby!” he said.

“Dad, Kim’s not going to hurt her!” David protested. Nevertheless, Dad ordered Kim to come over to him, but she refused. She just gave Dad a doggy dirty look and lay down under my bassinet. Everyone agreed, Kim was *very* protective of this precious jewel.

Once, when Aunt Gerry babysat me, Kim wouldn’t let her near me. My family backed down the driveway in their dark green 1955 Chevrolet station wagon, leaving the three of us alone. When Aunt Gerry went to pick me up, to her surprise and frustration, Kim wouldn’t budge and actually growled at her! There was no way Kim was going to leave her post. My aunt was wily, though: she threw a bone down the basement stairs and locked Kim down there. As much as Kim loved me, dogs will be dogs. She ran after it and felt duped. When she was finally let back in, she ran faster than Rin Tin Tin, right back to my side. Kim adored me, and at night she was always curled up on the floor, watching over me like a guardian angel.

The entire first year of my life was jotted down in a steno pad. Every movement, mood, and *bowel movement* was painstakingly kept in a journal by Mom. I was being monitored closely, just in case my health took a turn for the worse. Mom didn’t mind doing this at all. In fact, by observing me so closely, she became aware that something wasn’t right with me. Dad

sometimes became impatient with her very detailed account of everything and felt at times that she was *looking* for problems that didn't exist. "My God, Olga, you're so bent on every single detail, you'd think this steno pad belonged to a detective working on an unsolved murder!" Mom just ignored him most of the time, but it did create some tension between the two of them.

As much as Mom wanted to believe that everything was all right, she couldn't shake the feeling that I was different. As the months went by, Mom became more and more convinced that something wasn't right. She kept comparing me to what my brothers had done at the same age, and even though her pediatrician kept assuring her that I was normal, that not every baby does everything at the same time, Mom was not convinced. She took me to two other doctors, seeking second and third opinions. One sleepless night, she woke up my dad, telling him that she believed that I had cerebral palsy. Dad didn't think he had heard her correctly, but she repeated the same words with equal conviction in her voice.

The following morning, Mom brought up the subject again. "Jack, we need to talk about Geri. She is not progressing normally."

"Olga . . . the doctors say she is fine, just a little slower."

"Jack, I don't care what the doctors say. They don't see her day in and day out. They see her once a month for about thirty minutes!"

He cut her off, waving his arms. "And they are the *doctors!* Did *you* go to Harvard?"

"Jack, I know Geri has cerebral palsy. David started crawling at six and a half months, and Fred was crawling by eight months. Geri hasn't even tried to crawl yet, and she's almost a year old!"

"What makes you believe that she has cerebral palsy? I mean, there are other conditions that it could be as well."

"Do you remember when I took that job in Maine for the summer, as a nanny?"

"Well, yes, but what does that . . . ?"

"Jack, they had a twelve-year-old daughter with cerebral palsy. Her mother, Anna, gave me a crash course on cerebral palsy. She wanted me to fully understand Ann's condition, so that I could be more able to care for her properly."

Dad was stunned, not least because the girl's name was Ann and that is my middle name. "Did you name Geri after this other child?" Mom admitted that, in fact, she had. She loved the Turner family and wanted to

pay tribute to Ann. Dad had always assumed I was named after his mother, Anna Jewell.

Naming me was one thing, but Dad was beginning to understand that Mom's intuition wasn't something to be ignored, so they promptly made an appointment with a specialist in downtown Buffalo. The doctor there was the first to agree with Mom. After examining me, he believed that there was definitely something not right developmentally. In fact, he even suggested that they give me up before they become too attached. "What?!" Mom was stunned, to say the least. "She will be a year old next month! It's a little late to not get attached, don't you think?"

"Listen, I know you think I am being cruel to suggest giving her up, but believe me, it is the best thing for you and the child." The doctor had been through this routine time and again and was used to this reaction; he felt with absolute conviction that it was the right thing to do, to spare families of any further grief down the road.

Mom was furious. "Well, does she or does she not have cerebral palsy?"

"We will have to run some tests to find out conclusively. However, I have seen babies like this before, and I can tell you that most likely she will never be able to walk, and she probably has mental retardation. It is my professional opinion that these babies are much better cared for in state institutions. They have qualified staff who give the absolute best care possible to these unfortunate children. I assure you that the pain of giving up your daughter at this point is nothing compared to the future heartache and financial burdens these babies ultimately come into the world with."

Dad was beside himself. "The only financial burden we have right now is paying your astronomically high specialist fee! What is your specialty, doctor? Is your degree in Insensitive, Stupid, and Assholiness training?"

"I understand your anger, Mr. Jewell, but I know what I'm talking about."

As far as my parents were concerned, regardless of what diagnosis I was given, they would absolutely never hand me over to the state. Mom believed that I was put into their lives for a reason, and it was their responsibility to care for me. She understood that it might not be the option for everyone, but in her heart of hearts she knew she couldn't live with herself if she did anything other than provide a loving home for me. "No one's going to rip this family apart. If anyone should try, they're going to have to get past Kim first!" Not another word was ever said about giving me away. End of story.

My parents were so frustrated and overwhelmed. They went to at least six doctors over the following year, seeking second, third, and fourth opinions

and getting nowhere, or so it seemed. She decided to call Anna Turner. The Turners knew Mom now had a daughter, but Mom didn't want to worry them with her own concerns. Now it finally occurred to her what a valuable resource they might be. After all, they had been through this whole ordeal with their daughter. Mom had a lot of anxiety about calling them but didn't know where else to turn. She felt better simply by hearing the lovely calm voice of Anna Turner on the other end of the line. "Hello?"

"Anna, it's Olga."

"Oh, how wonderful to hear from you! I haven't gotten a letter from you in quite some time. Is everything all right, dear?"

"Well, truthfully, I'm calling because I need some advice."

"Oh? About what?"

"It's about Geri. Anna, I don't mean to upset you, but I think Geri has cerebral palsy just like Ann." There was a deep silence. "Anna, did you hear what I just said?"

"Yes, of course I did, child. I have been waiting for this call."

Mom's eyes welled up with tears. "What do you mean?"

"Ever since we heard about Geri's traumatic birth, her lack of oxygen, we believed that there might be further consequences down the road, but it wasn't our place to raise these concerns. If everything had turned out okay, then we would have worried you needlessly. You had to be the one to mention it first."

"Oh, Anna, it has been a nightmare. She is almost a year old, and she can't even sit up on her own yet! And the doctors! Last week we were told it was best to give Geri to the state, to have her institutionalized!" Anna wasn't the least bit surprised, as she was told the same thing 22 years earlier. She asked Mom how my dad felt about the situation. Mom explained that, although he became short-tempered at times, he was not about to give me up. However, they didn't know where to turn or where the best-qualified help was. "She hasn't even been officially diagnosed yet," Mom explained. Anna was a no-nonsense type of person and didn't waste any time pointing Mom in the right direction.

She suggested that she call the March of Dimes Foundation. Mom was surprised, as she had always thought that their cause was the fight against polio. At one time, that is what the March of Dimes represented. In fact, it was Eddie Cantor who coined the phrase "March of Dimes" as a campaign in theaters to raise money to help the fight against polio. But by 1956, the March of Dimes had expanded its scope to the prevention and treatment of

all birth defects. Mom couldn't thank her friend enough, and Anna told her that she could call her anytime.

Mom called the March of Dimes Foundation in New York City. The woman she spoke with was supportive and didn't once suggest giving me to the state. She explained how crucial it was for me to be diagnosed as quickly as possible so early intervention and therapy could begin immediately. She gave Mom the names of two very good doctors in New York City and said an appointment was well worth the train or plane ride. When Mom hung up, she realized there was some truth in what the first specialist had said: a trip to NYC wasn't in their budget.

When Mom told Dad about her call to the March of Dimes Foundation and how she was directed to these two wonderful doctors in the city, he seemed a bit overwhelmed. His concern was the same as hers. How were they ever going to afford such a trip? The next day, before Mom could even dial one of the New York numbers, the phone rang. It was Anna, who told Mom that she'd just become aware of a fabulous organization called the United Cerebral Palsy Foundation, UCP for short. Some of the best doctors on the forefront of cerebral palsy research were in southern California, making groundbreaking progress with children. Dr. Margaret Jones and Dr. Kenneth Jacques were the forerunners in the field at UCLA. "You must take Geri to California!" exclaimed Anna. Mom could only laugh. "What is so funny, Olga?"

"Oh Anna, Jack is going to lose his mind!"

"Well, let him lose his mind, dear. You take that baby to California, I tell you!"

"But . . ."

"No buts about it!" Mom knew Anna was right, and whatever the cost, they would find the money somehow.

The time came to tell the boys about the trip to California and that their baby sister might have cerebral palsy. The whole family sat down for dinner, which always began with a prayer, and thanked the Lord for their meals, which tonight was Hungarian goulash and Buffalo wings. Dad told the boys that their mother and sister were going to take a trip to California to see some doctors there who would help their little sister. Fred didn't quite understand. "Is she sick, Daddy?" David punched his younger brother in the arm.

"No, she is not sick," my dad calmly explained, "but she has some kind of a disability." Although David and Fred had already heard the term cerebral palsy one night when they were lying awake, this was one meal of

Hungarian goulash and Buffalo wings the boys would remember for a long time to come.

As much as Mom wanted to get on a plane the next morning, she knew it was next to impossible. There was so much to do to prepare for such a huge trip. The first thing she had to do was call Dr. Jacques to schedule an appointment for me. To her surprise, Dr. Jacques did not have an opening until February 14th, several months away! "You must be joking. My daughter may have cerebral palsy!" Dr. Jacques' assistant understood Mom's frustration, but unless there was a cancellation, there was really nothing she could do. Mom tried to explain that they were coming all the way from Buffalo, New York.

"Mrs. Jewell, the doctor is seeing children from as far away as Peru. Try not to view this as a delay, but rather as a needed time for preparation." How could this woman possibly know what it felt like for the parent of a baby with a disability? To be told that the doctor couldn't see them for at least six months felt like an eternity.

Then she was hit with another thought. "Are there that many babies with cerebral palsy?"

"I'm afraid there are, Mrs. Jewell, as well as a host of many other disabling conditions."

"What about Dr. Margaret Jones? I was given her name as well."

"Dr. Jones and Dr. Jacques both have about the same length waiting list. Trust me when I say this: there is so much you must accomplish to make this trip as comfortable as you possibly can, for yourself and your child. You must consider where you'll stay, how much to budget for meals, and, after your baby is diagnosed, what therapy programs to begin. Please take this time as a blessing, so that you can plan this trip very carefully, minimizing any surprises." As much as Mom wanted to scream, this woman's logic actually did make sense. She thanked my mom for her patience and scheduled my appointment for Valentine's Day.

The assistant in Los Angeles couldn't have been more correct; there was so much to do. In fact, in the process, Mom convinced Dad that they should actually *move* the entire family to California! So now they were preparing for not one trip, but two. Dad and the boys were going to drive out to California at the end of June, so David and Fred could finish the school year. Fred couldn't have been happier; he was still young enough to welcome the excitement of change. David, on the other hand, wasn't quite as thrilled with the idea. He had been looking forward to starting school in the

fall with all his friends. He didn't want to leave his relatives either. Fred tried to convince him how much fun California would be, but there was little that would change this boy's mind. In a way, David left a part of his heart in Buffalo (buried under six feet of snow). This move to California was definitely a sacrifice for his baby sister, but he loved me with all of his heart.

In any case, everyone was going to California, just like Lucy and Ricky. Everything was falling into place, and, as fate would have it, Mom's niece, Diana, had just moved out to California with her newlywed husband, Charlie. Mom asked Diana if she could stay with her for about three months. Diana was thrilled! She missed her relatives after leaving Buffalo. Charlie was in the air force, stationed at Edwards Air Force Base in Lancaster, California. "Aunt Olga, we live in the desert! It is the complete opposite of Buffalo. I'm talking tumbleweeds, cacti, and sand!" Even though Lancaster seemed like another world altogether, it is actually only about 40 miles north of Los Angeles.

It worked out perfectly for everyone, and my parents couldn't express their gratitude enough for Charlie and Diana's willingness to open their home to them. It relieved a lot of stress, knowing that we had a place to stay temporarily. Mom still kept up her steno pad entries that she'd been recording since I came home from the hospital, although now she also kept adding to a checklist of things that needed to be done for the *big* trip to California.

Dad realized that he was probably going to have to walk away from his job security at DuPont. He had been steadily moving up the ladder of job positions; some coworkers even believed that had my father stayed with DuPont, he would have become the CEO. So, in essence, everyone in my family made sacrifices for me. My dad not only was forced to start over for himself, but for his entire family of five. The process of finding employment in California, giving up a home that he had purchased through his G.I. Bill loan, and uprooting every conceivable seed that had been planted was quite an undertaking!

They decided to put their home on the market, even though they would probably take a loss on the sale. They didn't have a lot of equity in it, and there was no longer the beautiful maple tree in the center of the lawn. In fact, they found out very quickly that it was too costly to remove the tree altogether, as its roots snarled all over the entire property. The FOR SALE sign was posted next to the huge tree stump, so my mom stuck a potted plant on the stump. (I'm sure *no one* noticed the tree after that, Mom.) There was

tremendous stress in the Jewell household, but there was also much hope and anticipation.

We were booked on Pan Am Airlines and arrived in California a couple of days before our appointment with Dr. Jacques. It was a long trip that included a layover in Chicago, with us finally landing in Los Angeles around midnight. Diana and Charlie were at the airport to greet us. I actually slept for the entire car ride from the airport to Lancaster. Diana mentioned what a wonderful, good baby I was. Mom laughed, saying, "Most of the time." She explained that I was probably just coming down from a sugar rush, that all I had to eat on the plane were cherry Life Savers. How symbolic that cherry Life Savers kept my little tummy filled on this lifesaving trip across the country . . . especially considering that what would follow wasn't always going to be a bowl full of cherries.

Mom and Diana stayed up for a while visiting. Diana was thrilled to have her Aunt Olga staying with her. There were not that many neighbors, unless you counted all the jackrabbits that roamed freely. The desert was beautiful though, and as Mom passed the large bay window, she couldn't help but notice the dark sky filled with what looked like a hundred stars. "Wow! Are there always this many stars in the sky?"

Diana explained that it was one of the most mesmerizing and calming aspects of the desert, seeing all the cosmic stars twinkling on a clear night. "You might want to focus on one and make a wish," she said. Mom searched for the brightest star she could see that night and wished for her daughter to get the best possible care she could have. In a way, I already had.

The next morning, Mom carried me into the kitchen where Diana had prepared breakfast for us. Diana couldn't help but notice that I couldn't hold my head up very well. It was obvious to her that even though I was a little past 18 months old, in some ways I was developmentally at the age of six months. Mom explained that yes, I was delayed, but that with the right doctors and therapies, I would catch up. Like most people, Diana had never heard of cerebral palsy before and hadn't quite known what to expect. Frankly, there is no way to totally prepare for seeing an 18-month-old baby developmentally equivalent to a six-month-old. Diana couldn't hide her pain at seeing my head still bobbing like an infant's.

Mom had grown accustomed to receiving shocked responses from family members, friends, and even total strangers. But sometimes, my sunny smile actually put others at ease instantly. In the face of everything, I was a happy baby. This was something that inspired Mom daily. The strong front that

Mom showed the world was genuine, but she was only human, and sometimes she did cry herself to sleep, praying that God would keep showing her the way. It was now February 12, with my long anticipated doctor appointment two days away. Charlie had arranged to take the day off so he could drive us there himself.

It was a clear windy morning in the desert that day. The sand swirled, and tumbleweed sometimes crossed our path, but there were no major delays. The beautiful scenic drive against the backdrop of the purple sky took a little more than an hour. Finding a parking space proved somewhat challenging, although it was free — unlike in medical parking structures today, which demand a week's salary for an hour's stay.

When we entered Dr. Jacques' waiting room, there were at least three other children who hadn't been seen yet. We signed in and waited. Finally, just before noon, my name was called. Dr. Kenneth Jacques was a soft-spoken man in his mid-forties. He took his time to ask a lot of questions. He finally said the words that Mom had been waiting to hear, "Geraldine definitely has cerebral palsy. In fact, if you don't mind, I would like to officially diagnose her at a symposium later on this afternoon at UCLA."

The symposium was attended by 300 medical students. At 2:30 p.m. I sat on top of a table, strapped in a little chair, and showed all the classic symptoms of cerebral palsy. I was diagnosed before an attentive audience — that was my first stage appearance. I was unaware of the seriousness of my first performance and pretty much laughed and giggled the entire time, to the delight of my audience. I didn't get a standing ovation, but there was applause as Dr. Jacques acknowledged Mom's willingness to have me diagnosed for them that afternoon. I'm sure I mistook the applause for my own performance, and if I could have taken a bow, I'm sure I would have.

I was diagnosed with having a combination of athetoid, ataxia, and spastic cerebral palsy. Even though Mom had suspected this was the case all along, it was nevertheless painful to hear it so clearly. These words carried a lot of weight; I now had a label. There was a sense of relief that I was finally diagnosed, but there was also a sharp pang. There were so many questions with no immediate answers. Would I develop speech soon? Would I be able to sit up on my own? Would I learn how to walk? All these questions and many others raced through Mom's mind. Dr. Jacques had the same answer for all of them: "We will have to wait and see."

The fact that I was diagnosed so young was a blessing. It gave me a gigantic head start in getting the intervention and therapies that I would

inevitably need throughout my lifetime. The earlier the issues are addressed, the more likely they can be worked with. Some of us will never have speech or be able to walk because of the extent of the injury to the brain. But even in these cases, early intervention will still make a difference. My parents always said that if they had to do it again, they would. Diagnosis was just the beginning of a long process that was challenging every step of the way. No family can ever remain the same after having a “special needs” child. The entire family dynamic changes forever.

Diagnosis is just the beginning. Once the reality sets in, there is the heart-break that every parent must feel after discovering that their baby will never be normal. There is the unspoken guilt that transpires, where the parents believe it is somehow their fault the child has a disability. If there are siblings involved, there is even more guilt to contend with. Does the child with the disability pick up on the guilt as well? I think so, but I also believe that with so much focus revolving around the physical achievement, however big or small, becomes a priority over emotional developments that inadvertently are put on the back burner.

After my stage debut at UCLA, Mom took me to Los Angeles twice a week to have physical and occupational therapy. We would board the train to L.A. in Lancaster at 6 a.m. every Tuesday and Thursday. Then we'd catch a cab to UCLA. Mom always stayed with the therapists, observing and learning how she could assist me. Each day I made a little more progress in developing my motor skills. I worked hard, fighting against the spastic and involuntary movements that oftentimes kept me awake at night. Falling asleep was never something that came easily to me. My right arm would always be flinging from one position to another, as if it had a mind of its own. No matter how tired I was, my arm was “awake.” This was challenging because I worked so hard and tired quickly.

The therapy kept both Mom and me busy, and the excitement that our family would be back together again very soon kept us going.