Life Is Short

(no pun intended)

Love, Laughter, and Learning to Enjoy Every Moment

FROM THE STARS OF TLC'S *THE LITTLE COUPLE*

Jennifer Arnold, MD, & Bill Klein

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HOWARD BOOKS
An Imprint of Simon & Schuster, Inc.
New York Nashville London Toronto Sydney New Delhi

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Bill and Jen

WHEN WE FIRST ENTERTAINED the idea of writing a book, we weren't entirely convinced that our liv would be of interest to others outside the sphere of our family and friends, and perhaps son colleagues. And maybe some viewers of our television show. And, okay, a few people from the Littl People community as well. And did we mention our moms?

But in fact, the process of working on this book has been a truly illuminating experience for us. has enabled us to look back and recognize incidents, coincidences, and intersections, uncovered gen and discovered patterns, challenges faced and obstacles overcome. We've discovered remarkab parallels in each other's lives that serve to reinforce what a sacred treasure our life trajectories hav been, what a blessing it is that we have found each other (especially after repeated near miss throughout our lives, as you'll see).

So yes, we have learned so very much in the process of working on this book, which makes sharin our stories—and our story (since you'll see we are two different people but we are also in many wa one)—more rewarding than we'd imagined possible. We may at first glance seem different, but mayb you'll find we're not as different as you might think. We realized that regardless of our stature, ou journey has a lot in common with other stories of people who have overcome great obstacles challenges—as well as other great romance stories of people whose love transcended the odds of the circumstances.

As parents, it has been so moving to revisit our own childhoods and talk to loved ones about tho years. Yes, ours is a tale of two people born with a physical disability that could have defined us. Bu instead we thrived and flourished, mostly because of the love and support of our families. They had conquer so many fears and make so many personal sacrifices to make sure our opportunities we boundless. They were the ones who made sure we understood that our physical limitations shou never compromise our dreams, that we could achieve anything we set our minds to. Because the believed in us, we believed in ourselves, too. And as a result of those beliefs, we achieved even mo than we ever dreamed of. And now, with our own children, we get to put those hard-earned beliefs in practice.

One really fun aspect of our story is just how parallel our lives had been. We were both born wit the same type of dwarfism and we had both received treatment at the very same hospitals and from th very same doctors, sometimes even at the very same time. In fact, as you'll read later, we had even m as children.

That first encounter was followed by a string of near misses and close encounters over the ensuin years that in retrospect may seem too oddly coincidental to be true. But when we finally did meet, w recognized each other as soul mates, destined to be together. As we got to know each other, we wer amazed at the parallel emotional journeys we had taken as well—as you will see in these pages.

In short (no pun intended), this book has given us the rare opportunity to step back and look how character and events weave our lives together, and provide new insights into each other an ourselves. We may continue to juggle crises—challenges growing our family, Jen's recent cancer, Bill

more recent surgeries—but having found and built a life with each other makes us feel equipped wi
superpowers to battle anything that comes our way.

So, we are thankful—thankful that we have each other, and thankful for our kids, our family ar
friends, colleagues, and what feels like a great extended family of viewers. And we are thankful for yo
dear reader.

Jen

MY ARRIVAL!

WHEN I WAS YOUNG, just beginning to be "me," I had a theory about why I was smaller than everybo else. In my theory, my mother had purposely put contact lenses in my eyes so that I would see th world from a different perspective, that of a Little Person. I believed that one day, my mother wou remove the lenses, and when she did, I would actually be average sized. I thought it was actually son part of a bigger plan she had for me, almost as if she was doing it to teach me a lesson. Since then, have come to find out that many persons with significant physical and/or mental challenges ofte rationalize their difference as the result of a greater plan for themselves or the world.

I wasn't unhappy being a Little Person. Being a Little Person has always been and will always b normal to me. Even at a young age, I was used to the challenge of being a Little Person in an averag size world. For me, it wasn't like an accident occurred where my physical or mental capabiliti changed. I was used to step stools, and always having my clothes altered, used to being observed an pointed at by strangers, and I was used to trips to the doctor in the hospital that would make oth people keel over in exhaustion. But I didn't have time to feel that way. My parents always reminded m to count my blessings and be grateful for the things that were good in my life and that it could alwa be worse. I was raised not to focus on the negative, but be thankful for the positive. My paren embraced me to the degree that I thought other people might even be jealous of me.

My birth, my big arrival, happened on March 12, 1974, at St. Anthony's Hospital in St. Petersbur Florida, and was nothing short of harrowing. My mother was expecting a completely healthy baby, a she had had an uneventful pregnancy. My parents, David and Judy Arnold, were young, just twenty one, and completely overjoyed to be having their first child. However, the difficulties starte immediately in the delivery room. Not only did I come out feet first, which is very risky for a vagin delivery, but my mother was in labor for more than twenty-four hours before that. By the time I final emerged, she was hemorrhaging, I wasn't breathing, and both of us almost died.

At least I weighed seven pounds, eleven ounces, a good, healthy size. But my respiratory distre was definitely life threatening, and I had two large hematomas under my scalp, which, with m disproportionally large head, made the situation even more dire. Although doctors knew somethin was terribly wrong with me right away, nobody knew exactly what it was. My parents were told I ha "water on the brain" or hydrocephalus, which had all sorts of terrifying neurological implication Doctors went as far as to say it would likely cause me to be mentally challenged to some degree, if lived at all. It turns out that it wasn't hydrocephalus at all, but rather hydrops. Hydrops is a conditio in which fluid or edema accumulates in multiple body parts of a newborn. This is a rare condition, b a known complication for babies born with dwarfism.

I was only at St. Anthony's Hospital long enough for an intensive care neonatal transport vehicle t race there, sirens blaring, snatch me out of the delivery room, and rush me to All Children's Hospit several miles away. Here was the best neonatal intensive care unit (NICU) in St. Petersburg—in fac one of the best NICUs in all of southwest Florida. My mother didn't even have a chance to lay eyes o me before they took me away. She was still so out of it from all the anesthesia and pain medication they had given her that she didn't even know what was happening. She had lost so much blood th she needed two transfusions and a week in the hospital to recover. I recall my mom telling me th although she didn't get to see me for some time, her parents, my grandmother and Papa, had seen m and kept telling her not to listen to the doctors. They were certain that I was perfectly perfect and w going to be fine.

I was seven days old when she finally got to come to the NICU to meet me. Before she got ther she had heard so many terrifying terms to describe my condition, she had no idea what to expect. N matter how many issues the doctors enumerated and described, she didn't fear bonding with me. Sh totally loved me and only loved me that much more when she finally saw me.

My mom had a strong faith that God would take care of her small family, as He had neve presented her with an impossible situation or guided her wrong before. In fact, to this day, she credi her faith with getting her through my birth, which undercut the happiest day of her life wi extraordinary, terrifying unknowns. Her motherly instincts kicked in with a vengeance, and sh instantly became my protector, advocate, and supporter with everything she had.

My mother was not shy about expressing that at first glance she and my father were not the ide parents for me. They were young, practically broke, and very naïve. But, they got through it all wi strength and perseverance.

I had two traumatic weeks in the NICU. Even after my respiratory distress became less lif threatening, I still had many problems. The doctors were throwing out all kinds of diagnoses, bu through no fault of their own, they didn't hit on skeletal dysplasia. It was not a well-known diagnos and often it can be difficult to see the physical features of skeletal dysplasia soon after birth. For th moment, the doctors and my parents were just happy I no longer needed assistance breathing. Th neonatologists were still concerned about the hydrops, though they hoped it would resolve on its own

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MY PARENTS HAD been married for about a year when I was born. They had met at a Winn-Dix supermarket in St. Petersburg, where my mother was a part-time cashier and my father was manager. My father had a crush on my mother from the moment he saw her, but the feeling wasn't, least at first, mutual. When he learned she loved horses enough to save all her paychecks to buy on he capitalized on their common interest. He loved horses, too, having been raised around them. Whe he heard about my mother's purchase, he knew the perfect gift—a bridle. She was so impressed th he had tuned in to her interest that the romance budded immediately.

When my mother became pregnant, my parents moved into a little apartment in my matern grandparents' house in St. Petersburg. My grandfather, aka Papa, had converted the two-car garage o the house into a cozy apartment for them. My grandparents wanted my mother nearby, and with th baby coming, there was the added benefit of a houseful of people who could help them out—besid my grandmother, my mother's two younger sisters, my aunts Barbara and Chrissy, still lived at hom Barbara was sixteen, five years younger than Mom, and Chrissy was eleven. I grew up very close both my aunts. My uncle Wayne, who was just finishing high school at the time, also lived there.

My mother set up a beautiful nursery for me in the corner of the apartment, with the nicest crib sh could buy and a wardrobe full of pink onesies and bonnets. She was half terrified, then thrilled when was finally released from the NICU. She did her absolute best not to be too consumed with the sta of my future health.

My trips to the pediatrician were far more frequent than those of newborns without issues. As th months went by and my pediatrician kept tracking my height, weight, and head circumference, I ke slipping further and further off the chart for height and weight, even as I climbed the chart in hea circumference. Very concerned with my body mass, the pediatricians diagnosed me as "failing t thrive." They thought maybe it was a nutrition issue, plain and simple—that my mom wasn't feedi me enough, which is not unusual for a first-time mother. That possibility terrified my mom, wh thought that if I had malnutrition, child services might come to intervene and take me away. She trie so hard to make me eat more, she was beside herself! I mean, how much baby food and formula can baby tolerate? Because no one had diagnosed me with a form of dwarfism, they didn't realize th nutrition and food quantity was never an issue. My condition was rare, and the pediatricians were on going through a process of elimination, but they had my mother frantic.

Then came the next stressor. Right before my first birthday, we moved to a small rental apartmen in Orlando, a hundred miles from St. Petersburg, after my father accepted a job from my mother uncle. He was going to be managing a string of gas stations in the boomtown. My aunt Barbara, wi her parents' permission, moved with us and stayed a year.

The Walt Disney World Resort had just opened, although it was so small and new that there wer only three operating hotels on its whole forty square miles. However, because of the resort, the ci was already the hottest, hippest town in Florida. My mother got a part-time job waitressing at the Fo Wilderness area inside the park. Fort Wilderness was a vacation spot within Disney World with rusti cabins and campsites featuring a Wild West theme. My mom had to dress the part of a cowgirl, but sh didn't mind. She made many friends working there that she might not have met otherwise.

The first thing my parents did after the move was find a new pediatrician. Without knowing anyon with kids to give them references, they took a chance with Pediatrics Associates of Orlando, a grou practice not too far from our neighborhood. By the purest stroke of luck, the doctor in the group wh saw me first was Dr. Colin Condron, who turned out to be the link to determining my diagnosis. H had done his pediatric training at Johns Hopkins Hospital in Baltimore, Maryland, which was th finest pediatric orthopedic unit in the country, with specialized clinics for genetic-based issue including dwarfism. He told my mother he wanted her to take me to the Moore Clinic, a geneti clinic, as he thought they could confirm my diagnosis. He also arranged to have all our travel expens paid for by the hospital by enrolling me as a participant in a study currently underway. Back then wasn't unusual for academic hospitals to admit a patient with a rare or unusual diagnosis f evaluation.

I spent two weeks at the Moore Clinic, undergoing every medical workup possible. What goo fortune to have on my case Dr. Victor A. McKusick, a professor of medicine and medical genetics a Johns Hopkins Hospital with a reputation around the world for his expertise in unusual heredita diseases! He is often referred to as the father of clinical genetics and was the original author *Mendelian Inheritance in Man*, the most extensive database of all inheritable diseases. He was the fir person to diagnose me with spondyloepiphyseal dysplasia (SED), type Strudwick, the specific type dwarfism I had been born with. I believe he did this with a physical examination and a few X-rays.

SED is a type of skeletal dysplasia that involves significant skeletal abnormalities affecting the spin long bones, and joints. What the diagnosis meant for me was a childhood filled with orthoped

surgeries just to maintain mobility. SED is characterized by anomalies of the growth plates, joints, an spine, resulting in debilitating deformities such a scoliosis, knock knee, early osteoarthritis and joi degradation in your twenties, and other major joint problems. SED is rare, occurring in only about on in one hundred thousand births. Although it can be passed down from an abnormal gene from on parent, the majority of cases result from spontaneous mutations. Unfortunately, it turned out my cas was quite severe, and Dr. McKusick said I'd need many surgeries.

The fact that Dr. Condron had had such great training and expertise to identify that I likely had skeletal dysplasia and sent me to the specialists at Johns Hopkins Hospital early was a miracle. C course, once Dr. Condron got me to the Moore Clinic, my parents also got to meet someone wh would forever change our lives, Steven E. Kopits, MD. Dr. Kopits would become my orthoped surgeon and my lifesaver. At the time we met him, Dr. Kopits was the chief resident of pediatr orthopedics at Johns Hopkins Hospital, a position he cherished. He was from a long line of orthoped physicians, as both his father and grandfather were orthopedic surgeons in Hungary, his nativ country. After World War II, the Kopits family left Hungary and settled in Argentina, where *my* D Kopits got his medical degree at the Universidad de Buenos Aires. He then came to the United State doing his internship at Union Memorial Hospital in Baltimore and his residency at Johns Hopkin Hospital. It was then and there that his interest in patients with skeletal dysplasias was born. Not on was he a talented and dedicated physician and surgeon, but he also invented procedures no one ha ever tried before that often led to lifesaving treatments for children with skeletal dysplasias. He w somehow able to see a patient's deformity and tailor a surgical procedure to make what was n functional before work. There were times when Dr. Kopits would come out of the operating room an tell a patient's parents that he used a technique he had never used before during the operation, but t da, it worked, and he expected outstanding results!

Dr. Kopits hadn't always been a specialist in dwarfism. However, because Johns Hopkins had suc a large patient population with genetic illnesses, he found himself working with many genetic-base orthopedic problems, and his passion soon became the skeletal deformities of dwarfism. He had to me that it was evident to him that this was a unique patient population with unique issues, which n one had yet taken an interest in caring for.

Dr. Kopits was certifiably a hero, a miracle maker, to each and every Little Person who had th pleasure of being his patient. In fact, to those whom I know who were blessed enough to see him, h was infinitely more than a physician. We all considered him a beloved friend and a true member of ou families.

According to my mother, that first trip to Johns Hopkins Hospital and the Moore Clinic was muc more traumatic for her than for me. She had absolutely no idea what to expect, and two weeks seeme like forever, so she was in a whirlwind of fear. On the one hand, she was relieved to have gotten diagnosis for me, but she was equally overwhelmed by that diagnosis. One of the genetic specialis gave her an informational pamphlet about the size of a comic book that was filled with black-and-whi photos of different people with my condition. The picture pages showed the severe orthoped complications and deformities of children and adults. It was enough to scare her to death.

Dr. Kopits, a miracle worker to parents as well as patients, assured my mother that I would be we taken care of and that my prognosis was fairly good, but the list of surgeries he thought I would nee throughout my life was something no parent wanted to hear. It was clear it wasn't going to be easy.

My first surgery was about a year later, when I was two. It was probably the biggest surgery I'd ev have, a cervical spine fusion on account of the instability in my spine. I had to have my top tw vertebrae, C1 and C2, fused together. These two are the highest on the spine, right behind the sku

and when they are as unstable as mine were, any significant fall or jolt to one's head or back cou
cause paralysis, or worse. The fusion essentially turned those two vertebrae into a solid piec
However, it also meant I would have limited mobility in turning my head from side to side and flexi
up and down.

The fusion was difficult, and I was under the knife for at least nine hours while my paren
anxiously paced back and forth in the designated waiting area outside the operating room. The surge
involved taking bone from my hip to use as the "glue" for the fusion itself. Then, my spine w
carefully manipulated and aligned to Dr. Kopits's satisfaction. Next, he secured my head and neck b
placing me in a halo. A halo is a contraption that holds your neck stable after surgery while you heal.
involved four metal screws bolted into the four corners of my skull affixed with a circular metal ri
around my head—where the name halo comes from—with bars that went down from the halo a
attached to a belt-like fixture anchored at my waist.

I guess I looked pretty beaten up when I came out of the operating room. I was in the halo and w
admitted to the Pediatric Critical Care Unit. Even though all this had been explained to my moth
beforehand, and she thought she knew what to expect, she still fainted when she first got sight of m
in the recovery room. This would turn out to be a recurrent thing for my mom, so much so that D
Kopits started carrying smelling salts every time he met my mom in the recovery room.

My mom had to take me home in the halo to heal for about twelve weeks, which wasn't easy for h
first experience of surgery for me. She made the best of it. She said carrying me around was ea
because the halo device functioned like an oversized handle, and I was so light. She could grab me b
the bar anchored to the belt at my waist.

After I was discharged from the hospital, my mother and I flew home to Orlando where my au
Barbara would help me recover. However, I have come to realize that things don't always go smoothl
or as you hope, in these situations. I had come down with some sort of bad cold, which in itself wasn
the problem. The crisis began when my mom was at work, and my dad and Papa, who was visitin
from St. Petersburg, were at home with me and Dad tried to give me a dose of cold medicine. This wa
when giving children over-the-counter cold medicines was recommended by pediatricians, and I got s
upset about the taste of it that I started thrashing my legs around and kicked so hard I literally force
out the front two screws in my skull that held the halo in place.

My mother got a desperate call from my dad to get home immediately, if not faster. When sh
busted through the front door and into the living room, she found my dad and Papa standing rock-sti
on either side of me, looking terrified, not daring to move a muscle as they held my head in place.

"What the heck is holding her head going to do? We need to secure her head!" my mom yelled a
she ran to grab towels to stabilize my head within the halo and then to the phone to call 911.

My first memory ever is of riding in the back of the ambulance that came for me. The lights we
flashing, and my parents were tucking towels around my head, trying to make sure I was secured f
the trip to the hospital. Only one of them could go with me, so my dad offered to go, and my mo
followed in her car. Once the back door closed and the ambulance started to move, I remember m
dad singing me rhyming songs he made up on the spot to distract me while holding a tiny stuffed lio
he brought with us. I still remember the words—*"the flying lion stops the crying."* He sang it all the wa
to the hospital in an effort to calm me down.

My dad was always the creative one, with a great imagination, whether or not there was a
emergency. He loved creating stories and tales to make me feel better, and his plan usually worke
The "flying lion," made famous in the ambulance, became so special that my dad would later use hi
as a character in stories that became a full series. To this day, I still remember the plot lines.

My mom was always the tough one, always getting the job done. Their roles were complementa and equally important. My mom was already anxiously pacing the emergency room of Orlan Regional Medical Center when the paramedics raced me in on the stretcher. An adult orthoped surgeon, Dr. Johnson, met us there. At that time, he had never seen this type of halo before, let alone head halo that was displaced and semidangling. He and his staff began trying to communicate with D Kopits's office at Johns Hopkins Hospital. When they were told he was in South America and n reachable (this was the era before cell phones), the situation became increasingly intense. I w admitted to the hospital while my entire family, the office in Baltimore, and Dr. Johnson tried to reac Dr. Kopits to get instructions on how to replace the halo. Dr. Johnson didn't want to just react witho speaking to Dr. Kopits. However, because of the time passing and concern for injury to my spinal co if I moved, he offered to attempt to replace the halo.

However, my parents really wanted to wait for Dr. Kopits, confident somebody would reach hi The last thing they wanted was for someone not familiar with the halo to mess things up and paraly me forever. They had been warned that this was a possibility. They figured as long as I was in th hospital, secured, and monitored closely, I was safe.

Four days after I was admitted, there was still no word from Dr. Kopits. Dr. Johnson announced h and his team were going to have to take me into surgery to try to reset the halo. As terrified as m parents were, they agreed to go ahead.

Just as the surgical team was prepping me for the OR, into the waiting area walked Dr. Kopits! M mother and father practically fainted at the sight of him, breaking down in tears and thanking God f a miracle.

According to Dr. Kopits, intuition told him he needed to call his office, and when he followed h instinct and checked in with the office in Baltimore, he heard what was going on with me in Florid He went straight to the airport, caught the next flight to Miami, and then drove the three hours Orlando at ninety miles an hour in a rental car. What made the story even more exceptional was th he was in South America to receive an honor for his orthopedic work back where he had trained, a he left right in the middle of the dinner to take care of me before he could even receive his award.

After he arrived at the hospital, Dr. Kopits spoke briefly with Dr. Johnson, and soon he wa scrubbed and ready to accompany him into the OR. The whole thing made my mom a firm believer Dr. Kopits's dedication to his patients. With Dr. Kopits's direction, the halo was resecured. As he lef Dr. Kopits hugged both my parents and said to my mom, "Little mother, I am going to teach you ho to care for the screws so this doesn't happen again." Dr. Kopits taught my mom how to tighten th screws in my halo, which had to be done every couple of days, and we never had another "ha emergency" again. Soon, I was back at home for the rest of my recovery.

The most unbelievable part of that whole story is that Dr. Kopits never charged my parents for a of it. I later heard of other stories about Dr. Kopits traveling across the country to care for one of h patients, and always without charge.

The spinal fusion was just the first of many surgeries I would have. It would be followed b numerous osteotomies on my hips, knees, and ankles. These osteotomies were corrective surgic procedures in which bones were broken in order to realign my deformities. Without these surgerie my bones would likely become so deformed that I would be wheelchair-bound. My first osteotomy w on my hip when I was three years old. My primary nurse at this surgery was named Donna, and sh became one of our closest friends. At each yearly checkup in Baltimore with Dr. Kopits, he would te me if this would be a year for one surgery or two, as he would often do two at once. Of most concer to him were my knock knees and the fact that my femurs were growing at different rates, causi

severe deformities that, if not corrected, might not be fixable down the line and would make me unab
to walk. My knock-knee legs made it extremely difficult for me to keep up. Walking long distances wa
difficult, so I'd have to use a stroller, wheelchair, or when I was old enough, a scooter for distance. A
school I had the aid of some device for distance for as long as I can remember. At Disney World, I ma
have gotten to jump the line in a wheelchair, but of course would have preferred to walk wit
everybody else.

Bill

IT'S A BOY!

MY MOTHER AND FATHER, William Walter Klein, Sr., and Barbara Jane Diecidue, were both from Lon Island, New York. They grew up only a few miles from each other, as my father was from Levittown, five-minute drive from Mom's hometown of North Massapequa. They met for the first time when m mother was in her senior year of high school, and my father, three years older, was home on leav from the army. He had been stationed at a base in Alaska.

They started their relationship as pen pals. A friend of my mother's was "pen palling" with m father, which was a common thing to do with soldiers back then, and she thought my mother wou enjoy it, too. Mom didn't know it, but this friend, a former girlfriend of Dad's, suspected the two mig be a good match.

My parents' first in-person date was actually when my father was home on Long Island for twenty-one-day leave before being shipped to Southeast Asia for a tour of duty in Vietnam. By then, h and my mother had already been "dating by mail" for one year. The story goes that when Dad came Mom's house to take her out, Mom's younger sister, Lori, answered the door. According to Mom, Da probably thought that Lori was his date and was surprised when his real date, the little prepp schoolgirl named Barbara (my mother), popped up behind her.

Dad volunteered to serve in Vietnam, and in 1970 he was deployed to serve one tour of dut Shortly after arriving, he volunteered to serve as a door gunner on a UH-1H helicopter and w immediately assigned to an aviation detachment stationed in Phu Bai. Afterward, his unit wa relocated to an airbase in Da Nang. When not flying, Dad and other members of his unit visite orphanages in hopes of helping some of the kids displaced by the war. I think that is what my father most proud of. It speaks to both his character and the character of the other servicemen who serve with him in Vietnam. Like most veterans, my dad never really speaks about Vietnam or the war. know he was (and still is) proud to have served our country.

I was born on October 13, 1974, at Mid Island Hospital (now St. Joseph's) in Bethpage, Lon Island. The doctors knew immediately that something was wrong.

To begin with, I was cyanotic, a blue baby, which meant that I had some sort of heart malformatio that prevented my blood from being fully oxygenated. I was in respiratory distress and had to b provided with oxygen in order to breathe. But there was also something really wrong with m proportions. I was seventeen inches long, fairly normal, but the concern was I was all head and tors with very short appendages, so there was definitely something not right.

My parents were actually taller than average. My father was exactly six feet, when the averag height for men at that time was five-eight. In fact, my mother was five-eight, four inches taller than th

average woman. There was tall stature in the genetic pools of both their families as well. My mothe brother is six-four, and an uncle on Dad's side is six-two.

It has been speculated that my father's exposure to Agent Orange while serving in Vietnam was contributing factor to my short stature. The exposure, which can result in flu-like symptoms amor other things, is now known to denature the sperm's DNA, causing random mutations. But they don know for sure if what happened was a mutation associated with exposure to Agent Orange or if it wa a true random genetic mutation.

The delivery took a long time. At one point the doctor sent my father home and promised to ca when I was closer to making my debut. Just as my father was arriving at my maternal grandparen house, the phone rang. A nurse from the hospital said the doctor wanted my father to know I had bee born, but that something was terribly wrong. He added to "not rush." *Not rush?!* My father drove breakneck speed from North Massapequa back to Bethpage in less than five minutes, a ride th normally took double that. The doctor who had delivered me had already disappeared. According to m father, he was so seemingly nervous or unable to negotiate the terms of my novel condition that h never returned, ever. None of us ever saw him again.

Dad demanded to see me as soon as he got to the hospital. The baby nurse in the nursery held m up so he could see me through the glass window. He was in shock when he realized the severity of m condition. As the day progressed, the doctors and nurses were at a loss for words. But wanting to he in some way, they moved my mom to a private room, something that was unheard of then. With Mor not yet knowing exactly what was going on with me, Dad made the decision to decline the priva room, fearing it would cause her undue stress. He also knew that this decision would dictate how m life would be, and he didn't want me to be segregated because of other people's prejudices, even if the intentions were good.

Nobody knew how my mother would handle the news, so for a couple of days, the medical tea taking care of me avoided bringing me to her. Because of the difficult delivery, she was heavi medicated, and they told her I was still getting treatment. Finally, three days after I was born, m mother absolutely demanded to see me, so a nurse on the unit got up enough nerve to carry me i hand me over, and run out of the room.

My mother's sister was a nurse in the hospital, but even she didn't know exactly what was going o She knew the buzz that it was bad and everybody was upset, but other than that, my condition was st a mystery. I was baptized many times over just in case I didn't make it.

I can't fathom the fear my mother must have had. Her first baby, her little bundle of pride and jo had arrived, and everyone on the medical staff was scratching his or her head, bewildered. You ca almost imagine my mom, in her room agonizing, scared, wondering, and waiting, the door closed to th conversation of the doctors going on in the hall. The secrecy made it even more difficult, as the docto seemed to be mumbling things to each other, but not to her. My parents only had each other.

At one point, the pediatrician came in to talk to my mother. She told Mom she didn't know wh was wrong with me; as far as she could tell, I only presented as "short."

"He's a dwarf, isn't he?" my mother blurted out, which caused the pediatrician to almost fall over disbelief. Mom knew of somebody whose child had growth issues, and doctors were considerin dwarfism. Otherwise, she probably never would have come up with this idea, but the pediatrician w in no way ready to agree.

My breathing issues continued for at least four days, so finally the decision was made to send me the NICU at Nassau County Medical Center in East Meadow, now called Nassau University Medic Center. The neonatologist from that unit who had been assigned to my case came with the NIC

transport to collect me. I was lying in the isolette that I would be transferred in, and he wheeled m
over to my mother and told her she could say good-bye to me now, if she wanted.

"No, I am not saying good-bye to him," she responded with defiance. "This is *'hello,'* and I will se
him later." She said that after she gave the specialist this correction, she and I made complete ey
contact, which is very unusual for a newborn. With my big blue eyes, I told her, "I am not goin
anywhere, Mom. I'll see you soon."

Not long after my departure in the ambulance, Mom was also discharged and my parents were l
the side of my isolette within an hour. They kept vigil in the NICU for hours every single day for th
next three weeks. There was one doctor on the unit who said he thought I had a form of dwarfis
called achondroplasia, because of my very large head and very short arms and legs. This was the mo
common form of dwarfism, characterized by short limbs and a large head with a prominent forehea
Apparently, if you stretched out my arms and lifted them up, they didn't reach the middle of my head.

Having a baby in critical care without a diagnosis was extremely hard on my parents. They had tw
or three relatives and five or six friends who were having babies at the same time they were, and tho
babies were all healthy and thriving. In time, they learned there was a better shot at getting hit l
lightning three times over than being born with my condition, but at the moment, they only ha
questions without answers. It was almost a miracle that I made it.

A month later, I was finally well enough to get out of the NICU. Most of our family and friend
avoided us, because nobody knew the best way to deal with a situation like ours. The ones who d
come around were awkwardly delighted to meet me. All this was causing my mother unbelievab
stress and isolation, which was breaking her heart. But never for an instant did my parents falter
their love for me.

My parents worried about how I would be accepted, and I still had many very critical health issu
they needed to deal with. My breathing often sounded like a wheezing squeak of an underoiled se
saw. Sometimes, these episodes were so critical, I had to be hospitalized. This happened six or seve
times my first year of life. When I was nine months old, I almost died. I had just been released fro
the hospital after another breathing episode, and had been given penicillin to take at home. To this da
Mom is still suspicious that it was a bad batch, recalling its horrible smell. Whatever the reason, th
penicillin or not, within days of getting home I became so dangerously dehydrated that I had to l
rushed back to the hospital, where I spent a solid month in guarded condition. Meanwhile, my paren
were still dealing with a tangle of diagnoses and treatments.

My mother followed the doctor's direction diligently and sought out every bit of wisdom she cou
find. My father, too, was unbelievably accepting of my condition. Many times, according
psychologists who understand the stress that a less than "perfect" baby places on a marriage, it is th
man who really struggles with the idea of a long-term disability. Before I was born, they had decided
name me William Junior, after my father. Mom offered to let Dad choose another name, particular
the name that would eventually be given to my youngest brother, Joseph Scott, if he didn't want me
be his namesake. My father would have none of it. "He is William Junior," he announced with since
pride.

My father was a graduate of the Nassau County Police Academy and a police officer on Lon
Island. He was perfect for the job—tall, athletic, a people person, and a hard worker. My mother was
loving stay-at-home mom. She worked as a bank teller before I was born, but once I arrived, sh
always intended to stay home with me. She just didn't realize her new role was going to requi
navigating this much stress.

When I was still an infant, my mother actually had a nervous breakdown. Obviously, I was to

young to remember it, but she was hospitalized for a full week and a half and was put on tranquilizer
It must have been terrifying for her, so young, scared, naïve, and in desperate need of answers, whic
nobody had.

Mom dealt with the situation as best she could, but she found it difficult to express how she fe
about having a child with such pervasive health problems. People could say such nasty things whe
she took me out for even simple things, like to run errands. Their comments were devastating to Mom
"Look at the midget, look at the dwarf!" or "Look how funny looking he is!" One time somebod
actually said I should have died in childbirth, and that both Mom and I would have been better off.

Dad was just the opposite. While the negative comments about me hurt him, he would shrug the
off. His main concern was my health and finding out exactly what my condition was so we could de
with it. Dad always said that people handle things differently and that his way of dealing with adversi
was to work the problem, something I emulated as I got older. I used my dad's approach of "workin
the problem" to handle a lot of the obstacles in my path.

People all too often made inconsiderate comments or asked ignorant questions, to the point whe
my mother became afraid to leave the house.

One story I love involves an event that took place in the supermarket when I was about four. Mo
and I had gotten into a bit of a disagreement. Most likely, I was just being obnoxious and stubborn
But a woman overheard us from the other side of the store. She ran toward us, and when she reache
me in the cart, she declared to my mother in a stern voice, "How dare you yell at that infant!" Befo
Mom could respond, I said something that, well, let's just say it wasn't Mom's proudest moment. Th
stranger was as stunned as Mom was embarrassed and quietly slunk away.

I wasn't always that bad. But I was a tough son of a gun to take shopping. I had a way of lettin
myself out of the stroller by sliding down and slipping out of the harness. I might have been the size f
the baby stroller, but I wasn't a slobbering infant. I was like a very young Houdini. If Mom wa
preoccupied looking at clothes, I could escape and disappear on her. I was fast, too, and could wa
under anything without clunking my head. Sometimes, the only way Mom could find me was whe
she heard a stranger saying, "Oh, my gosh, look at the size of him!" and then she'd give me that loo
and scoop me up. She had captured her little rascal, but I knew I could escape again soon.

There were strategies Mom devised to buffer me—and herself—from these awkward situation
Whenever she could, she tried to go to the store with friends. There was strength in numbers. Sh
figured that way people would be less willing to make comments. There would still be the rude perso
who would point and say something inappropriate, but now she had support. Her friends would te
the gawkers to leave us both alone, that we are just out shopping, just like them.

• • •

I WAS DEFINITELY a bit of a medical nightmare and enigma at the same time, but I was at least makin
progress in some categories. As for physical milestones, I was behind, but cognitively I was ahead o
the charts. For example, I was six months delayed in walking, partly because my head was so big.
would have to drag it around when I crawled, which consequently made it harder to hold up when
finally walked. However, my verbal skills were light-years ahead of the average range. I started talkin
at ten months. By fourteen months, I could speak in full sentences, my favorite being, "Momm
please get me some milk because I am hungry." I looked like an infant but had the vocabulary of a fift
grader, like a Benjamin Button without the wrinkles. What you lack in one area, you tend t
compensate for in others, which might explain why I was such a talker.

My parents tried to be as well-connected and informed as they possibly could be, but it wasn't eas
Mom kept calling different organizations that might have knowledge or information about dwarfis
By the time I was six months old, she had found out about the Moore Clinic at Johns Hopki
Hospital. The geneticist working there was Victor McKusick, the top physician in growth issues a
dwarfism. Mom made an appointment for me, and Mom, Dad, and I headed to Baltimore.

Dr. McKusick was an extremely tall man. He had a portrait in his office of him sitting in a cha
with a patient, an Amish Little Person, perched on his lap. The first thing he told my mother was th
the doctors at Nassau County Medical Center were right about the dwarfism, but were wrong
thinking that it was achondroplasia. He wasn't ready to commit to exactly what type affected me aft
only one visit, but he was going to put together a profile of my presenting conditions and send it to a
of the doctors he knew around the world who were working with growth issues. If I ended up being
a unique category all by myself, Dr. McKusick said he would name it "Klein Syndrome," after me. H
charm and bedside manner finally had my mother feeling a little more at ease.

I was fourteen months old when I finally met Dr. Steven Kopits, who was also Jen's doctor at John
Hopkins. He agreed with Dr. McKusick that my dwarfism wasn't achondroplasia. I ha
spondyloepiphyseal dysplasia (SED), which manifested itself differently. People with SED a
characterized by more proportionate arms and legs; hip, knee, and ankle instability and deformitie
and increasing curvature of the spine, including kyphosis lordosis and scoliosis. Unfortunately, SED
also characterized by many requisite surgeries to correct the irregular growth of the lower limbs.

First memories are always a bit suspect, because there is always a possibility that the memory is ju
created from overhearing someone else's story. But this was not the case with my first memory. I wa
three years old, and I woke up in the operating room. I remember the lighting, the smells, the sound
and the movements of the scene. I remember the bright, absolute white lights, the way I was lying o
the operating table, and the crowd of people around me, even though their eyes weren't really focuse
on me. There was that distinct smell that still haunts me, that postanesthesia stench that sticks insi
your lungs and your nasal cavity for a long, long time. I could hear that all-too-familiar Hungaria
accent of Dr. Kopits speaking in a sharp tone. I remember a nurse saying something to me, although
can't remember the details.

• • •

EVER SINCE I can remember, Mom was always at my side. She supported me through my toughest time
and encouraged me to be better. When I was very young, she would stay in my room through the nig
just to watch over me. When I started school, she would greet me with a smile when I came home an
ask about my day. Hugs weren't in short supply, either. We were a close family, and my mother alway
embraced us with a warm hug—to congratulate, to heal, to say I love you. My father, too, was ve
supportive and always there for me. He refused to let other people's doubts dictate the way my paren
raised me.

My mother was beautiful. Her hairstyle went through different phases, from shorter bobs to th
longer wavy style when that was in fashion. When she was happy, she smiled with her eyes. When sh
was unhappy, I could see it in the way she looked at me. She could also express surpris
disappointment, anger, fear, and joy by the way she looked at me.

Mom was very stylish, even when money was tight. She had her two seasons of outfits, shorts an
short-sleeve shirts or sundresses in the summer, and blouses, pants or jeans, sweaters, and heavy coa
in the winter. She was particularly fond of her coats.

My father was in great physical shape in his younger years. He worked hard and kept up h appearance. His hair changed with the fashion of the times, and I followed his lead with things lik how to part mine. However, when he went with the then-stylish perm, I elected to abstain even if meant I was "uncool."

Both my parents raised the kids, but my father was the authoritative one, and I admired him. H size and demeanor commanded attention. As a police officer, he was a respected figure, and everyon who had an association with our family saw him that way. Dad wore a uniform well. He looked like cop, for sure. He wore his hat down a bit to the brow, shoulders out, back straight, no slouching. H holstered sidearm was a revolver when I was young, but he graduated to a nine-millimeter later on. was proud that my father was a cop. He had power that not many other dads had, and I though foolishly, that his power therefore extended to me. To mess with me was to mess with a cop, and could kick some serious butt like he did. When Dad looked at me, I knew it. When he smiled, I laughed along with it. When he was angry or disappointed, he looked through me. I felt it without th need for words. I wasn't a big troublemaker, but I got my fair share of both looks.

I am the oldest of my parents' three sons. My brother, Tom, was born two years and ten month after me, and Joe came along four years and two months after that. They did not have my conditio but they saw me go through many of my procedures and recoveries. Even with my physical limitation being the oldest meant being responsible for my siblings. It was my duty to keep them in line, despi the fact that they quickly surpassed me in height at young ages. Tom eventually stopped growing whe he was six-foot-four, and Joe reached a height of six feet. The two would always help me out when was home and bedridden after a surgery. I often felt bad that I dominated my parents' time. But the never held it against me. In fact, they both looked up to me as their big brother.

I was built like a Mack truck, and I always fought my battles aggressively. The age differenc between my brothers and me was big enough that they were a pain when we weren't getting alon Feats of strength were often needed to reinforce my place atop the sibling hierarchy. From tradition punches and chokeholds to the occasional throwing of a little brother clear across a room, I did wh needed to be done to continue to command the respect an older brother needs to possess. That w kind of the way it went. My brothers were younger than me, and even though they were taller as we they were not stronger. I managed to successfully establish myself as the oldest, and I was strong for person short in stature, so, physically, I always won.

Jen

DRAGONS AND FAIRIES

BY THE TIME I started kindergarten, my family had moved from our first apartment in downtow Orlando to a nice ranch house on a hill in one of the many planned communities that were popping u all over the greater Orlando area. My father's new job as a route salesman for Orange News Compar paid better and meant we could afford to buy something bigger, and my mother loved the idea of livin in this type of neighborhood. The communities were self-contained, family-friendly, and offered lots recreation and social events. They also had catchy names. Ours, called Rosemont, was on the shore Lake Orlando and only about a twenty-minute drive from Disney World and downtown.

Barbara came with us when we first moved, but then, after my grandparents divorced, m grandmother and aunt Chrissy came to live with us, too. My mother didn't mind her mother ar sisters living with us. In fact, she enjoyed it, as they were a big help. I grew up very close to Chris and Barbara. They were not only great as babysitters and playmates, but they would also let m accompany them on their dates with boyfriends or to their high school outings. This was a sign of ju how much they loved me.

Soon after my grandmother and aunt Chrissy moved in, my aunt Barbara moved back to S Petersburg to be with her high school sweetheart, Jack, who would later become her husband and m favorite uncle.

No matter where we lived, my mom always enjoyed making sure our home felt lived-in ar comfortable. She was a fantastic decorator, and to this day, I wonder if she missed her calling as a interior designer. Her flair for detail and organization meant every room was dressed to the nines.

My bedroom was no exception. My wallpaper had delicate flowers that climbed the walls from th floor to the ceiling, making it seem like I lived in a garden. Today, I might not find that floral look s attractive, but it was the rage in the early eighties. Need I say more? I had a four-poster bed decked o with a white eyelet ruffled bedspread and crowned with a matching canopy. The nightstand ar dresser completed the bedroom furniture set. My favorite stuffed animals and dolls were usually line up along the built-in shelves, as my mom was a bit of a neat freak and liked me to keep them orderl To accommodate my short stature, my dad put a lower rod in my closet, not only making it easy for m to get to my clothes, but also doubling the space.

There were definitely enough adults around that my parents didn't need to hire many babysitter Because my father worked during the day, my mother chose to work at Walt Disney World at nigh thereby assuring one or the other would be at home with me. If my dad worked late, my grandmoth would take care of me. It was nice to have her in Orlando with us. We became very close, and sh became a true confidante to me as I grew up. Chrissy always helped, too. She and I were only eleve

years apart, so she was more like a big sister than an aunt. Although she went to high school durin the day, she went out of her way to spend lots of time with me after school and on weekends. Sh loved photography and writing and wanted to become a journalist. We would dress up in all sorts crazy outfits and take silly Polaroid pictures for hours. I have pictures of us dressed up as cowboys an Indians, Elvis and other entertainers, tennis players, you name it—we did it. We even set up a phot shoot with me hidden in the middle of all my stuffed animals, kind of like *Where's Waldo?* Chrissy ha great taste in music. She taught me how to sing the Beatles, Rod Stewart's "Hot Legs," and Elvis song We even made voice recordings of me impersonating famous artists as I sang some of their popula tunes. As we were both growing up together, my aunt Chrissy and I became best friends.

My grandmother had always been a stay-at-home mom. But now that she was divorced, she real wanted to get into the workforce and make some money. She found a job at Disney World as telephone operator for Buena Vista Communications. I used to love calling her on Disney's mai phone line and requesting "Lorraine Shipman, please." I admired how she had gone back to work aft dedicating all her time to raising her kids. I also admired how much pride she had in her job and ho seriously she took it. Like my parents, she worked full-time, but her hours were regular enough th she would be home in time to make dinner when my mother was doing her night shift.

My grandmother was someone I went to for advice and just pure comfort, especially if I had gotte into an argument with my mother and father. She somehow always knew the right thing to say, and all else failed, she would rub my back with "tickles" to make me feel better. She might have spoiled m just a *little*, but I loved her for that.

When my mom worked, she often came home after midnight. My dad was incredibly thoughtfu and not only would he wait up for her, he would often make her favorite meal, breakfast for dinn with bacon and eggs. My favorite nights were when he would let me wait up with him. I'd keep hi company in the kitchen while he set the table, prepared his pans, and tidied the kitchen.

Mostly, though, I was to be in bed with lights out long before my mother got home. This was m parents' one chance to be alone and decompress together. Our home was always neat as a pin an filled with love, but this was not an easy, pressure-free household. There was stress, both financial an emotional, on many fronts. There was the juggling of job schedules, surgeries, and travel for me, an like every family, dynamics to manage. However, somehow, my family always made sure I came first.

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I DIDN'T REALIZE I was a Little Person until I was six or seven years old. It didn't really matter much to m however, and I did all the things most kids at that age did. I went to birthday parties of kids in th neighborhood, played outside, and sped around the block on whatever bike I was currently riding, wi my dad or Aunt Chrissy following closely behind. Like most kids, I loved pretending, and dragons an fairies were my favorite characters. It was not unusual for all the neighborhood kids to gather on ou lawn while Aunt Chrissy, Dad, and I started a game of "dungeons and dragons."

My school, Rolling Hills Elementary, was directly behind our house, but in another subdivisio called Pine Hills. It was too far for me to walk, but too close for busing, so my mom or Grandm would drive me there and back, which wasn't horribly inconvenient for them. To get around th hallways, I had my Chubby Chopper, a tiny plastic yellow tricycle that fit me perfectly and moved lik a speedboat. My best friend was a girl named Cara, who lived so far at the outskirts of town that h property was like a farm, with tons of farm animals. I always looked forward to playdates at her hou for fun with her family's horses, cows, and goats.

When I was seven, my brother was born. My parents later told me that they had held off having second baby until they had genetic counseling to determine the odds of having another child wi dwarfism. Since neither of them was a Little Person, and my type of dwarfism is a dominant trait, th likelihood of the same genetic mutation was nominal. As much as my parents adored me, my mo didn't think she was capable of raising another child who needed so much medical attention. I thin she still feared for my own happiness and long-term potential, and didn't want another child to have go through the same struggles she saw me having to endure. It was very emotionally taxing for her an had taken a serious toll on her coping skills.

The morning my mother went into labor, I went to school, knowing that I was soon going to have baby brother. My parents named him David Eugene, and even though he had my dad's first name, h wasn't officially a junior. His middle name was chosen in honor of my grandfather Issac Euger Shipman. My grandfather, whom I called Papa, had four children—one son, my uncle Wayne, wh was the eldest, and after that, three girls. He had always wanted another boy, whom he wanted t name David Eugene. My papa had a heart attack days before my brother was born, so when my mo delivered my brother, they were both in the hospital. After the delivery, my mom called Papa, and th first thing he said was "How is my David Eugene doing?" That was how my brother got his name.

A year later, my papa had a second heart attack, and this one took his life. Even after m grandparents' divorce years before, I had stayed very close with my grandfather. He meant so much t me that some years after his death, I had a dream that I went up to heaven to visit him. I sat on his be where he was watching football, which he loved to do, and we had the most amazing conversation. H told me about the afterlife and that he was watching over us and that most important, he was all right

My brother was a full-term, average-statured newborn without any presenting medical issues aft birth. He was home with us in twenty-four hours. My parents were thrilled to have a second chil especially a boy, join the family. I don't recall being particularly excited or upset about having a bab brother, but I did know that I loved him from the moment he came home. He was a very cu newborn, and I liked holding him, but once he started walking and running around like a typic toddler, slowly morphing into a menace who liked to make a mess of my room and crash my slumb parties, it was a different story. Turns out brothers and sisters can be very different, not alway compatible, but always lovable.

I think some of the bantering David and I had growing up likely related to our age difference an the fact that he was a boy, which in my mind meant we didn't have much in common. It also migh have been because of all the medical attention I needed. With medical attention came other types attention from family and friends. I cannot imagine how hard that was for him. Because he wasn having surgeries all the time, I was also confused. I actually asked my mom one day, "So when doe David have his first operation?" Similarly, he even once asked my parents when he was going to hav his surgeries, possibly because he saw me getting presents and lots of attention before, during, an after all of mine. The strain of having a child in the family with complex medical needs can be challenge for both younger and older siblings.

Early childhood was at times good and at times bad. Yes, the house was more chaotic, and I had t share my family with my brother. But I was also at an age when kids really began to notice differenc between one another. My kindergarten graduation was the first time I noticed that I was truly short than everybody else. I remember an incident in the first grade when we were playing tag in the fiel and another boy yelled at me, "Why do you have such a big head?" I didn't acknowledge him at th time, but when I came home and reported this event to my dad, his response was, "Next time, tell hi it's because you have more brains!" That was my dad, always quick with funny retorts!

In second grade, the movie *Annie* came out, and I adored it. My good friend Kristie, who was budding theater buff, and I were bonded by our love for *Annie*. We would sing all the songs out lou together and watch the VHS over and over every time we had a playdate. These "girl times" we extraordinary, but when Kristie tried out for the part of Annie at one of our local theaters and landed i I was a little jealous for the first time. I wasn't envious in that mean way, as I knew Kristie made great Annie, and I even got to see her in one of her shows. But I, too, loved the character of Annie s much, and I had even dressed as her the previous Halloween, orange wig and all. I knew deep dow that I could be a good Annie. I wondered—if I had tried out, would I have gotten it? Or would the have dismissed me because I was a Little Person? I would never know, because I never tried out. Tha was a lesson I would learn from this experience. I knew I had limitations due to my stature, but yo can never succeed at something if you don't try.

As a young child with dwarfism, I missed some typical opportunities for fun. My parents wouldn allow me to go to water parks, even though all my friends were going, because despite swim lessons, couldn't swim, tread, or float in the water due to my skeletal dysplasia. I couldn't ride certain rides wi height restrictions at Disney World. Despite the fact that I really wanted to play the violin, my mo couldn't find an instrument small enough to fit me.

Things like this were very upsetting, but ultimately I learned I had to deal with these challenges an overcome them in order to be happy. If I was upset, my mother would always remind me that thes were minor defeats and there was so much more I could do. She would tell me not to wallow in se pity, as it wouldn't do me any good. She told me how much I had to be thankful for. My aunt Chriss would also advise me that no person or situation made us happy or sad. Our emotions were ou choice. As I grew older, I came to realize that if I wanted to be happy in life, I had to make myse happy, or at least not let obstacles or disappointments overpower me. This was the life I had bee given, and I needed, more important, *wanted* to make the most of it.

Of course growing up I had many positive experiences, too. Sports activities were not exactly in th cards for me, but I found other ways to participate in competitions. With my mom's encouragement, entered my very first dog, a miniature collie named April, in a special dog race for family pets at th Sanford-Orlando Kennel Club in Longwood. To my delight, she won honorable mention, and we bot went home with smiles and a ribbon.

Dogs, judgment-free and unconditionally loving, were a mainstay of my childhood. April was eve more important, because she was *my* dog, given *just to me* by my parents. Her previous owner was on of my mom's colleagues at Disney World, and she came to me when she was just out of he puppyhood. I nicknamed her Boo Boo (mostly because I was not a fan of her given name, April) an personally taught her many of her winning tricks. I was so proud when she won the special "Race You Pet" event at the greyhound racetrack. The best part was that the local newspaper ran a story featurin us. I might not have been Annie, but Boo Boo and I were stars.

Bill

Kindergarten, Here I Come!

I GREW UP IN PORT Jefferson Station, a typical suburban town on the North Shore of Long Island abo sixty miles east of New York City. The area was then called Terryville, a small hamlet in the town o Brookhaven. It was a typical suburban landscape, with newly built homes in three or four differe styles of ranches, split levels, and colonials.

My parents picked a house to buy in a location that would best serve my needs. They understoo that I was a Little Person who might have a problem with walking to and from school or climbing th steep three steps of a school bus, so they chose a house that bordered the schoolyard. My school da were still a couple of years off, but my parents were planning ahead, especially as "mainstreamin children with mental, emotional, and physical disabilities into the student population was ju beginning to become policy. My mother had heard from different people who had children who we "little" that it wasn't easy. These parents were having a hard time getting their children into th schools. The school districts didn't want to deal with issues or accommodations; they didn't want to c anything different for the kids, really. Even though the Education for All Handicapped Children Act o 1975 was now in place and schools had to provide for children who were different, my mother was st afraid there would be a glitch, and I would end up being steered toward a "special" school that cou accommodate me.

By taking my need for busing out of the equation, my mother had one less thing to worry about. house next to the school was perfect. Just a few hundred feet between our house and the back door the school meant no bus, minibus, or special bus after kindergarten. Just my Keds and backpack.

I started at the Boyle Road Elementary School when I was five years old. I took the bus at fir along with all the kids going to school for the first time, and it wasn't the easiest task to climb up th steps, but I did it. And once I got to school, I could see my house from the classroom, and on occasio I would look toward the backyard to see if there was any activity. Sometimes, I would see Mom doin something back there, but I didn't necessarily know what. I was happy and reassured that I could s her from school.

Mom had already taken a very active role in the school, which helped her feel a little in control our situation. Our neighbor, who was one of her best friends, had signed her up for the PTA befo she could even think about it. She came over one day and told Mom, "You are coming to the ne meeting, you are already a member, and you will love being involved." It was perfect, because m mother was on the shy side and not very outspoken. However, with that small push, she quickly mad herself known to the entire elementary school staff, teachers and administrators alike. She understoo that when you have a child with special needs, you need to be outspoken. For example, following th