



## Life Is Short (No Pun Intended): Love, Laughter, and Learning to Enjoy Every Moment

By Jennifer Arnold MD, Bill Klein

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From the beloved stars of TLC's *The Little Couple* comes an uplifting and moving behind-the-scenes account of how the pair met, fell in love, and overcame huge obstacles to become successful professionals and parents.

Jennifer Arnold and Bill Klein have inspired millions as stars of TLC's hit show *The Little Couple*. Though they both have dwarfism, they have knocked down every obstacle they have encountered together with a positive, can-do attitude. The show has featured the lives of Jennifer (a respected neonatologist) and Bill (a successful entrepreneur) from their marriage in 2009, to the launch of their pet shop, to the adoption of their children, to Jen's overcoming cancer.

Now, for the first time Jen and Bill are letting readers into their private lives with behind-the-scenes, never-before-told stories about how they fell in love, what inspires them, and the passions that drive their success.

Jen and Bill have a simple purpose in life: make the world a better place through encouragement and education. A must-have for fans of the show or anyone who has ever faced a difficult challenge, *Life Is Short (No Pun Intended)* gives readers a glance at what inspires these positive people to approach life with such optimism and share their lives with the public every day.

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### Editorial Review

#### About the Author

Jennifer Arnold, MD, graduated from the University of Miami with dual degrees in Biology and Psychology before going on to complete her medical degree at Johns Hopkins School of Medicine in Baltimore, MD in 2000. She is currently an attending neonatologist at Baylor College of Medicine and Medical Director of the Simulation Center at Texas Children's Hospital. Dr. Arnold is married to her best friend Bill Klein. They live in Houston, TX and have adopted two wonderful children. Jennifer and Bill are the stars of TLC's *The Little Couple*.

Bill Klein grew up on Long Island, NY. After earning a degree in Biology from NYU, Bill became an entrepreneur and inventor. Today, he plays an active role in every business he owns, including Candu Enterprises, where he and his wife Jennifer provide a variety of media-related services, including making appearances at schools and other institutions to aid in the campaign to stop bullying. Most recently, Bill created Rocky & Maggie's, a pet supply business named after the family dogs. Bill Klein is married to his best friend Jennifer Arnold. They live in Houston, TX and have adopted two fantastic children. Bill and Jennifer are the stars of TLC's *The Little Couple*.

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Life Is Short (No Pun Intended)

## CHAPTER ONE

### Jen



### My Arrival!

WHEN I WAS YOUNG, just beginning to be “me,” I had a theory about why I was smaller than everybody else. In my theory, my mother had purposely put contact lenses in my eyes so that I would see the world from a different perspective, that of a Little Person. I believed that one day, my mother would remove the lenses, and when she did, I would actually be average sized. I thought it was actually some part of a bigger plan she had for me, almost as if she was doing it to teach me a lesson. Since then, I have come to find out that many persons with significant physical and/or mental challenges often 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 be normal to me. Even at a young age, I was used to the challenge of being a Little Person in an average-size world. For me, it wasn't like an accident occurred where my physical or mental capabilities changed. I was used to step stools, and always having my clothes altered, used to being observed and pointed at by strangers, and I was used to trips to the doctor in the hospital that would make other people keel over in exhaustion. But I didn't have time to feel that way. My parents always reminded me to count my blessings and be grateful for the

things that were good in my life and that it could always be worse. I was raised not to focus on the negative, but be thankful for the positive. My parents 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. Petersburg, Florida, and was nothing short of harrowing. My mother was expecting a completely healthy baby, as 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 started immediately in the delivery room. Not only did I come out feet first, which is very risky for a vaginal delivery, but my mother was in labor for more than twenty-four hours before that. By the time I finally 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 distress was definitely life threatening, and I had two large hematomas under my scalp, which, with my disproportionately large head, made the situation even more dire. Although doctors knew something was terribly wrong with me right away, nobody knew exactly what it was. My parents were told I had "water on the brain" or hydrocephalus, which had all sorts of terrifying neurological implications. Doctors went as far as to say it would likely cause me to be mentally challenged to some degree, if I lived at all. It turns out that it wasn't hydrocephalus at all, but rather hydrops. Hydrops is a condition in which fluid or edema accumulates in multiple body parts of a newborn. This is a rare condition, but 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 to race there, sirens blaring, snatch me out of the delivery room, and rush me to All Children's Hospital several miles away. Here was the best neonatal intensive care unit (NICU) in St. Petersburg—in fact, one of the best NICUs in all of southwest Florida. My mother didn't even have a chance to lay eyes on me before they took me away. She was still so out of it from all the anesthesia and pain medications they had given her that she didn't even know what was happening. She had lost so much blood that she needed two transfusions and a week in the hospital to recover. I recall my mom telling me that although she didn't get to see me for some time, her parents, my grandmother and Papa, had seen me and kept telling her not to listen to the doctors. They were certain that I was perfectly perfect and was going to be fine.

I was seven days old when she finally got to come to the NICU to meet me. Before she got there, she had heard so many terrifying terms to describe my condition, she had no idea what to expect. No matter how many issues the doctors enumerated and described, she didn't fear bonding with me. She 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 never presented her with an impossible situation or guided her wrong before. In fact, to this day, she credits her faith with getting her through my birth, which undercut the happiest day of her life with extraordinary, terrifying unknowns. Her motherly instincts kicked in with a vengeance, and she 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 ideal parents for me. They were young, practically broke, and very naïve. But, they got through it all with strength and perseverance.

I had two traumatic weeks in the NICU. Even after my respiratory distress became less life-threatening, I still had many problems. The doctors were throwing out all kinds of diagnoses, but, through no fault of their own,

they didn't hit on skeletal dysplasia. It was not a well-known diagnosis and often it can be difficult to see the physical features of skeletal dysplasia soon after birth. For the moment, the doctors and my parents were just happy I no longer needed assistance breathing. The 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-Dixie supermarket in St. Petersburg, where my mother was a part-time cashier and my father was a manager. My father had a crush on my mother from the moment he saw her, but the feeling wasn't, at least at first, mutual. When he learned she loved horses enough to save all her paychecks to buy one, he capitalized on their common interest. He loved horses, too, having been raised around them. When he heard about my mother's purchase, he knew the perfect gift—a bridle. She was so impressed that 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 maternal grandparents' house in St. Petersburg. My grandfather, aka Papa, had converted the two-car garage of the house into a cozy apartment for them. My grandparents wanted my mother nearby, and with the baby coming, there was the added benefit of a houseful of people who could help them out—besides my grandmother, my mother's two younger sisters, my aunts Barbara and Chrissy, still lived at home. Barbara was sixteen, five years younger than Mom, and Chrissy was eleven. I grew up very close to 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 she could buy and a wardrobe full of pink onesies and bonnets. She was half terrified, then thrilled when I was finally released from the NICU. She did her absolute best not to be too consumed with the state of my future health.

My trips to the pediatrician were far more frequent than those of newborns without issues. As the months went by and my pediatrician kept tracking my height, weight, and head circumference, I kept slipping further and further off the chart for height and weight, even as I climbed the chart in head circumference. Very concerned with my body mass, the pediatricians diagnosed me as “failing to thrive.” They thought maybe it was a nutrition issue, plain and simple—that my mom wasn't feeding me enough, which is not unusual for a first-time mother. That possibility terrified my mom, who thought that if I had malnutrition, child services might come to intervene and take me away. She tried so hard to make me eat more, she was beside herself! I mean, how much baby food and formula can a baby tolerate? Because no one had diagnosed me with a form of dwarfism, they didn't realize that nutrition and food quantity was never an issue. My condition was rare, and the pediatricians were only 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 apartment in Orlando, a hundred miles from St. Petersburg, after my father accepted a job from my mother's uncle. He was going to be managing a string of gas stations in the boomtown. My aunt Barbara, with 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 were only three operating hotels on its whole forty square miles. However, because of the resort, the city was already the hottest, hippest town in Florida. My mother got a part-time job waitressing at the Fort Wilderness area inside the park. Fort Wilderness was a vacation spot within Disney World with rustic cabins and campsites featuring a Wild West theme. My mom had to dress the part of a cowgirl, but she 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 anyone with kids to give them references, they took a chance with Pediatrics Associates of Orlando, a group practice not too far from our neighborhood. By the purest stroke of luck, the doctor in the group who saw me first was Dr. Colin Condron, who turned out to be the link to determining my diagnosis. He had done his pediatric training at Johns Hopkins Hospital in Baltimore, Maryland, which was the finest pediatric orthopedic unit in the country, with specialized clinics for genetic-based issues, including dwarfism. He told my mother he wanted her to take me to the Moore Clinic, a genetics clinic, as he thought they could confirm my diagnosis. He also arranged to have all our travel expenses paid for by the hospital by enrolling me as a participant in a study currently underway. Back then it wasn't unusual for academic hospitals to admit a patient with a rare or unusual diagnosis for evaluation.

I spent two weeks at the Moore Clinic, undergoing every medical workup possible. What good fortune to have on my case Dr. Victor A. McKusick, a professor of medicine and medical genetics at Johns Hopkins Hospital with a reputation around the world for his expertise in unusual hereditary diseases! He is often referred to as the father of clinical genetics and was the original author of Mendelian Inheritance in Man, the most extensive database of all inheritable diseases. He was the first person to diagnose me with spondyloepiphyseal dysplasia (SED), type Strudwick, the specific type of 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 spine, long bones, and joints. What the diagnosis meant for me was a childhood filled with orthopedic surgeries just to maintain mobility. SED is characterized by anomalies of the growth plates, joints, and spine, resulting in debilitating deformities such as scoliosis, knock knee, early osteoarthritis and joint degradation in your twenties, and other major joint problems. SED is rare, occurring in only about one in one hundred thousand births. Although it can be passed down from an abnormal gene from one parent, the majority of cases result from spontaneous mutations. Unfortunately, it turned out my case 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 a skeletal dysplasia and sent me to the specialists at Johns Hopkins Hospital early was a miracle. Of course, once Dr. Condron got me to the Moore Clinic, my parents also got to meet someone who would forever change our lives, Steven E. Kopits, MD. Dr. Kopits would become my orthopedic surgeon and my lifesaver. At the time we met him, Dr. Kopits was the chief resident of pediatric orthopedics at Johns Hopkins Hospital, a position he cherished. He was from a long line of orthopedic physicians, as both his father and grandfather were orthopedic surgeons in Hungary, his native country. After World War II, the Kopits family left Hungary and settled in Argentina, where my Dr. Kopits got his medical degree at the Universidad de Buenos Aires. He then came to the United States, doing his internship at Union Memorial Hospital in Baltimore and his residency at Johns Hopkins Hospital. It was then and there that his interest in patients with skeletal dysplasias was born. Not only was he a talented and dedicated physician and surgeon, but he also invented procedures no one had ever tried before that often led to lifesaving treatments for children with skeletal dysplasias. He was somehow able to see a patient's deformity and tailor a surgical procedure to make what was not functional before work. There were times when Dr. Kopits would come out of the operating room and tell a patient's parents that he used a technique he had never used before during the operation, but ta-da, it worked, and he expected outstanding results!

Dr. Kopits hadn't always been a specialist in dwarfism. However, because Johns Hopkins had such a large patient population with genetic illnesses, he found himself working with many genetic-based orthopedic problems, and his passion soon became the skeletal deformities of dwarfism. He had told me that it was evident to him that this was a unique patient population with unique issues, which no 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 the pleasure of being his patient. In fact, to those whom I know who were blessed enough to see him, he was infinitely more than a physician. We all considered him a beloved friend and a true member of our families.

According to my mother, that first trip to Johns Hopkins Hospital and the Moore Clinic was much more traumatic for her than for me. She had absolutely no idea what to expect, and two weeks seemed like forever, so she was in a whirlwind of fear. On the one hand, she was relieved to have gotten a diagnosis for me, but she was equally overwhelmed by that diagnosis. One of the genetic specialists gave her an informational pamphlet about the size of a comic book that was filled with black-and-white photos of different people with my condition. The picture pages showed the severe orthopedic 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 well taken care of and that my prognosis was fairly good, but the list of surgeries he thought I would need 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 ever have, a cervical spine fusion on account of the instability in my spine. I had to have my top two vertebrae, C1 and C2, fused together. These two are the highest on the spine, right behind the skull, and when they are as unstable as mine were, any significant fall or jolt to one's head or back could cause paralysis, or worse. The fusion essentially turned those two vertebrae into a solid piece. However, it also meant I would have limited mobility in turning my head from side to side and flexing up and down.

The fusion was difficult, and I was under the knife for at least nine hours while my parents anxiously paced back and forth in the designated waiting area outside the operating room. The surgery involved taking bone from my hip to use as the "glue" for the fusion itself. Then, my spine was carefully manipulated and aligned to Dr. Kopits's satisfaction. Next, he secured my head and neck by placing me in a halo. A halo is a contraption that holds your neck stable after surgery while you heal. It involved four metal screws bolted into the four corners of my skull affixed with a circular metal ring around my head—where the name halo comes from—with bars that went down from the halo and 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 was admitted to the Pediatric Critical Care Unit. Even though all this had been explained to my mother beforehand, and she thought she knew what to expect, she still fainted when she first got sight of me in the recovery room. This would turn out to be a recurrent thing for my mom, so much so that Dr. 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 her first experience of surgery for me. She made the best of it. She said carrying me around was easy because the halo device functioned like an oversized handle, and I was so light. She could grab me by 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 aunt Barbara would help me recover. However, I have come to realize that things don't always go smoothly, or as you hope, in these situations. I had come down with some sort of bad cold, which in itself wasn't the problem. The crisis began when my mom was at work, and my dad and Papa, who was visiting from St. Petersburg, were at home with me and Dad tried to give me a dose of cold medicine. This was when giving children



over-the-counter cold medicines was recommended by pediatricians, and I got so upset about the taste of it that I started thrashing my legs around and kicked so hard I literally forced 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 she busted through the front door and into the living room, she found my dad and Papa standing rock-stiff 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 as 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 were flashing, and my parents were tucking towels around my head, trying to make sure I was secured for the trip to the hospital. Only one of them could go with me, so my dad offered to go, and my mom followed in her car. Once the back door closed and the ambulance started to move, I remember my dad singing me rhyming songs he made up on the spot to distract me while holding a tiny stuffed lion he brought with us. I still remember the words—“the flying lion stops the crying.” He sang it all the way 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 an emergency. He loved creating stories and tales to make me feel better, and his plan usually worked. The “flying lion,” made famous in the ambulance, became so special that my dad would later use him 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 complementary and equally important. My mom was already anxiously pacing the emergency room of Orlando Regional Medical Center when the paramedics raced me in on the stretcher. An adult orthopedic surgeon, Dr. Johnson, met us there. At that time, he had never seen this type of halo before, let alone a head halo that was displaced and semidangling. He and his staff began trying to communicate with Dr. Kopits’s office at Johns Hopkins Hospital. When they were told he was in South America and not reachable (this was the era before cell phones), the situation became increasingly intense. I was admitted to the hospital while my entire family, the office in Baltimore, and Dr. Johnson tried to reach Dr. Kopits to get instructions on how to replace the halo. Dr. Johnson didn’t want to just react without speaking to Dr. Kopits. However, because of the time passing and concern for injury to my spinal cord 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 him. The last thing they wanted was for someone not familiar with the halo to mess things up and paralyze me forever. They had been warned that this was a possibility. They figured as long as I was in the 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 he and his team were going to have to take me into surgery to try to reset the halo. As terrified as my 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! My mother and father practically fainted at the sight of him, breaking down in tears and thanking God for a miracle.

According to Dr. Kopits, intuition told him he needed to call his office, and when he followed his instinct and checked in with the office in Baltimore, he heard what was going on with me in Florida. He went

straight to the airport, caught the next flight to Miami, and then drove the three hours to Orlando at ninety miles an hour in a rental car. What made the story even more exceptional was that he was in South America to receive an honor for his orthopedic work back where he had trained, and 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 was scrubbed and ready to accompany him into the OR. The whole thing made my mom a firm believer in Dr. Kopits's dedication to his patients. With Dr. Kopits's direction, the halo was resecured. As he left, Dr. Kopits hugged both my parents and said to my mom, "Little mother, I am going to teach you how to care for the screws so this doesn't happen again." Dr. Kopits taught my mom how to tighten the screws in my halo, which had to be done every couple of days, and we never had another "halo 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 any of it. I later heard of other stories about Dr. Kopits traveling across the country to care for one of his patients, and always without charge.

The spinal fusion was just the first of many surgeries I would have. It would be followed by numerous osteotomies on my hips, knees, and ankles. These osteotomies were corrective surgical procedures in which bones were broken in order to realign my deformities. Without these surgeries, my bones would likely become so deformed that I would be wheelchair-bound. My first osteotomy was on my hip when I was three years old. My primary nurse at this surgery was named Donna, and she became one of our closest friends. At each yearly checkup in Baltimore with Dr. Kopits, he would tell me if this would be a year for one surgery or two, as he would often do two at once. Of most concern to him were my knock knees and the fact that my femurs were growing at different rates, causing severe deformities that, if not corrected, might not be fixable down the line and would make me unable to walk. My knock-knee legs made it extremely difficult for me to keep up. Walking long distances was difficult, so I'd have to use a stroller, wheelchair, or when I was old enough, a scooter for distance. At school I had the aid of some device for distance for as long as I can remember. At Disney World, I may have gotten to jump the line in a wheelchair, but of course would have preferred to walk with everybody else.

## **Users Review**

### **From reader reviews:**

#### **Sonja Johnson:**

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