

PRAISE FOR
Diary of a Beautiful Disaster

Diary of a Beautiful Disaster is authentic in a way that goes beyond honesty because of the depth of Kristin Bartzokis's insight. What I first read as honesty began to reveal itself as psychology, then philosophy and theology. Kristin's self-perception serves to universalize a totally unique experience. I highly recommend *Diary of a Beautiful Disaster* as a journey through what it means to be a completely, and unflinchingly, beautiful human being.

—DAVID ROCHE, humorist and author of
The Church of 80% Sincerity

A brave memoir by a young woman who was born with severe facial anomalies but managed, through sheer will and countless surgeries, to turn what began as a disaster into a life of love, achievement, and beauty.

—NICHOLAS GAGE, author of *Eleni* and *Greek Fire*

Diary of a Beautiful Disaster is a moving memoir, but more than that it is an honest, sincere front-row peek into one woman's ability to persevere, overcome, and find true acceptance. In Kristin's story, you will certainly find moments you can relate to and probably some moments you take issue with, too. However, throughout all of the difficult decisions she and her parents had to make regarding her care, how she chooses to pursue her life and happiness, and the choices she owns, you will be inspired and strengthened by her resolve and her commitment to living a full, fearless life. I truly enjoyed this book and Kristin's incredible storytelling!

I highly recommend it for anyone wrestling with self-acceptance and appearance diversity, and especially for parents who want reassurance and comfort when making major medical choices for their child. This book is not a how-to manual for life, but rather a how-I'm-doing-it, heart-to-heart conversation that will stick with you long after you finish the story. Kristin is a role model not just for other children and teens with craniofacial differences, but truly for anyone who wants to pursue a life committed to self-reliance, continual improvement, and personal resolve.

—ERICA MOSSHOLDER, executive director,
Children's Craniofacial Association

DIARY OF A
BEAUTIFUL
DISASTER

Kristin Bartzokis



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This book is dedicated to all those affected by craniofacial anomalies. Know you are never alone. So many of us are fighting a similar fight. Stay strong and choose to be positive. It makes all the difference.

* * *

To the medical staff involved in our reconstructive processes: Thank you for choosing this career path. You work tirelessly to bring a sense of normalcy to our lives.

* * *

A special thanks goes to my reconstructive surgeon, Dr. S. Anthony Wolfe. Your knowledge, skill, and dedication have impacted my life from the first moment my parents brought me to your office. I am forever grateful for every decision we made together.

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These pages tell the story of my life, the life of a woman in her early thirties who is afflicted with an unusual facial anomaly known as Treacher Collins syndrome. In deciding how best to tell my story, I felt a simple narrative approach would not properly convey the emotions I experienced as I dealt with various obstacles in my life. Though the narrative form worked well to tell the basic story of how I grew into the person I am today, it seemed inadequate to detail the most traumatic incidents of my life: my numerous craniofacial surgeries. To share my emotions surrounding those procedures, I needed a different approach, something more visceral, so I chose to relate the stories of my surgeries as journal entries. Those “entries” do not come verbatim from a diary, but from my recollections, the recollections of my parents, actual notes and letters written by my parents at the time of my surgeries, and medical records provided by my doctor.

These chapters create a more intimate, emotional understanding of those trying times. It’s one thing to read about an experience; it’s another to live in that very moment.

I interspersed journal entries from my perspective as well as from the vantage points of my mother, Pat, and my father, Chris. My parents have memories of surgeries I was too young to recall, and it was important to me to show how syndromes like mine affect the entire family, not just the patient.

Reliving certain moments was often difficult for me and for my parents, but I wanted to hold nothing back. What appears in the pages that follow is the unvarnished truth about my life.

Growing Up Ordinary

From the moment my parents realized I would have a difficult life ahead of me, they vowed to do everything in their power to ensure my day-to-day life would be as ordinary as possible. They didn't know the details of what I would face over the years, whether my future operations would break me, or if I'd be at the receiving end of cruel remarks from my peers, but they knew they had to raise me to believe I could accomplish anything. They instilled in me an unlimited outlook on life, which allowed me to forget about my syndrome and focus on all the ways that I was similar to my peers, rather than how I was different.

The fact that I had a syndrome did not cause my parents to shelter me or hold me back from doing things other children did. From the very beginning, they raised me to understand my limitations: no swimming while wearing my hearing aid and no horseplay after a surgery. Other than that, I never heard the phrases *you can't*, *you won't*, or *you'll never*. I could accomplish anything as long as I put forth the effort. With that upbringing, I gained the confidence to explore a variety of activities without worrying that my disability might be a hindrance. In my mind, I had no disability when it came to confronting challenges. I was just like anybody else.

My parents knew they had to deal with the negatives in my life, but they didn't have to dwell on them. They treated my problems as mere inconveniences rather than as major obstacles. More importantly, they took great pains to impart that attitude to me, and to this day that is how I live my life. I thrived because my parents gave me the chance to live a full and happy life. I'm convinced that this

unlimited outlook is the most important reason for my success. It allowed me to remain positive during the hard times.

I'm grateful when people tell me they are impressed by the kind of person I have become. This validates the way I live my life. I don't let much bother me, and I take everything life throws at me in stride. The way I see things, there's only one way for me to deal with my difficulties: with acceptance. I did not ask for a life with problems. I never wanted to deal with the emotional scarring and physical pain associated with my disability, nor would I ever wish that kind of life on anyone else. Nevertheless, I have learned to deal with my anomalies as best I can.

Many people complain about the hand they've been dealt in life. They harbor ill will toward others who are more fortunate and they are wary of the world around them, often waiting to pounce on the next unsuspecting person who might offend them in some way, real or imagined.

I refuse to live this way. My condition is no one's fault. It's not a curse or prison sentence; it's a way of life. Holding a grudge against the world would do nothing to improve my situation, so I refuse to entertain any thoughts along those lines. Of course, I have my difficult moments, but I steady myself and move on. Dwelling on the unchangeable will not reverse my situation. I owe this mentality to my parents, because they always found a way to help me assimilate to my surroundings.

From birth I was taught to believe that my life was limitless. When I was sixteen weeks old, my parents enrolled me in the Fort Lauderdale Oral School. Even though I was still an infant, they felt I should begin the long process of dealing with my syndrome. I

had a hearing impairment and needed to learn how to differentiate between sounds.

I received my first hearing aid when I was six weeks old, which meant that right away my young mind was actively listening to the formation of words and utterances, just like normal-hearing children did. Even if I was nowhere near ready to speak, the sooner I concentrated on using my ears, the more I would rely on their functionality. Because of this, my speech therapist encouraged my mom to cover her mouth when she spoke. I would be forced to hear the words instead of learning to read lips.

Every step my parents took in my development exposed me to a more fulfilling and independent life. But even with that, there were limitations they realized they could not exceed. As amazing as it would have been for me to learn how to speak Greek with my extended family, the way my father did, the speech therapist urged my parents to teach me only one language. My young mind needed to focus on understanding and perfecting English above all else. Also, learning sign language was not an option. The goal was for me to hear independently and not rely on other methods of communication.

By following the therapist's instructions, my parents eliminated a crutch I could have used as I grew older. Though I now wish I could both speak Greek and respond to those who sign to me, I'm thankful for the strict emphasis my therapist placed on learning only one language. It forced me to learn to listen.

I spent ten years in speech therapy. In the beginning, certain letters were difficult for me to pronounce because my cleft palate and narrow nasal passages prevented the normal production of sound. To assist me in overcoming this problem, the therapists

turned my learning time into playtime. For the letter *P*, they would place a tiny scrap of tissue on their palms. If I pronounced the *P* sound correctly, the tissue would float into the air. If I spoke through my nose, the tissue would not move. Boy, did I want to make that tissue dance! I enjoyed playing these games so much that I never fully realized I was actually working.

In my later years of therapy, I would read books out loud while using a device that measured nasal emission. The end piece of the device rested in one of my nostrils, and whenever I spoke through my nose, a Styrofoam bead in the tube portion of the device rose up and down. My goal would be to read the chapter without making the bead rise unnecessarily. I usually succeeded.

As the years passed, therapy began to bore me. I wanted to play outside with my friends rather than sit at home with the therapist learning how to speak from my diaphragm. I felt alone during speech therapy. Everyone else my age already knew how to speak properly. Why didn't I? But I slogged on and continued with my lessons because I knew it was for the best.

One day, however, I received some great news. With a huge smile on her face, my speech therapist told me she would no longer be coming over to my house for lessons. I had achieved all the goals she once set for me, and her services were no longer needed. After ten years, my lessons were officially over.

So many emotions coursed through me that day. I felt relieved, excited, and accomplished. I had conquered a major challenge in my life. Now I knew how to use my voice properly; now I could communicate clearly with other people. This no doubt would allow me to fit in better in various social settings.

Focusing on what I *could* do gave me a positive outlook on life. By concentrating on what I shared with others, I considered

myself an equal instead of an outcast. Sometimes, however, that attitude was tested. On one occasion, when I was four years old and attending mainstream preschool, I sat on the floor of a local theatre waiting for a children's production of a play to start. At one point, a young blond-haired boy seated in front of me turned around and asked me if I was deaf. I blinked a couple of times and then replied hesitantly, "Yes." His question surprised me because my friend, who was seated next to me, and I were talking while we waited for the show to start. The boy in front of us had obviously heard us speaking with each other. He therefore must have known I was able to hear my friend's comments. How else would I have been able to respond to him? So why, I wondered, did the boy think I was deaf? To me, at that young age, I thought the definition of deaf was the complete inability to hear. In my mind, since I could hear, I wasn't deaf.

But at the time I did not feel like debating that point with the inquisitive boy in front of me; I just wanted to be left alone. So I said yes to him when he asked if I was deaf. In truth, though, his inquiry confused me, and made me wonder if maybe there was something wrong with my hearing. Up to that point, I didn't think I had a hearing problem. I felt as though my hearing aid was just an extension of me. And in every other respect, I was just a normal preschooler, who, at the time, was sitting cross-legged on the wooden floor waiting for the fun to start. Now, however, I began to wonder.

Later that night, my mom confirmed to me that people who suffered from deafness could not hear a single thing. That was not the case with me. Though the entryways to my ear canals were covered with skin, I still could hear some small sounds unassisted.

With the help of my hearing aid, however, I could hear everything. This unusual condition caused me to live in an interchangeable world of sound and silence, depending on whether my hearing aid was on or off. Although this didn't bother me very much, it did become annoying at times, particularly when my hearing aid batteries died without warning. Regardless, I was finally able to understand and appreciate my auditory abilities and limitations. I was not deaf, but I did have some form of hearing impairment.

This newfound knowledge was not without its advantages. In fact, it gave me quite a bit of control over my life, especially when I was a young child. There were several occasions when my parents would yell at me for one thing or another. Rather than listen to their ranting, I would simply turn off my hearing aid as they scolded me. From my perspective, if I could not hear them, I could not get into trouble. Immediately, I would notice smirks form across their previously cross faces. They were chuckling about what I had done; they thought I was being funny, and they would laugh at my ingenuity. With the simple turn of an on/off button, I realized I had found a clever way to get out of trouble. Although I did not know it at the time, self-awareness was beginning to take hold of me.

I know it's difficult to believe, but when I was young, I really did feel normal. I understood at an early age that my life was somehow different than most people's. I knew my peers never visited reconstructive surgeons on a regular basis. I knew they didn't plan their summers around operations. And I knew they had more forgiving childhoods than I did. In truth, however, even though I knew I had more problems than most other children, I considered my issues minor. The difficulties that made my life unique never forced me to feel anything but ordinary. I didn't feel special or different or brave.

This was simply my life, and there was nothing very unusual about it. If an obstacle came my way, I dealt with it, just like anybody would. That I had to endure surgical procedures every so often was not extraordinary; it was just a fact of life. I simply had more obstacles to deal with than most children, but I felt like an ordinary girl living an ordinary life, and never saw myself surviving on more courage or strength than any other kid my age.

I felt so ordinary because my parents always let me be a child. They never tried to dissuade me from engaging in activities that concerned them, even when they knew some frightening things about my syndrome that I didn't. Limited airflow is one of the drawbacks of having a narrow nasal passage. Before having surgery on my mandible and maxilla structures (lower and upper jaw), breathing at night would be bothersome, not only to me, but also to anyone around me. I would often snore loudly, and sometimes I would stop breathing temporarily until I woke up gasping for air. My parents never told me how awful I sounded, or how frightened they were that I would stop breathing completely, until after I had an operation that opened up my airway. Despite my problematic nighttime breathing, they still willingly sent me to sleepovers and sleepaway camps. Had I known the severity of my snoring, I probably would have been too ashamed to sleep anywhere but my own room. Rather than fuel my inhibitions, however, they let me live the way other children did.

As the years progressed, my mind-set began to shift. Maybe I was a little different. Though I still considered myself to be equal to my peers and fully capable of achieving my goals, insecurities slowly began to creep into my thoughts. I realized that even though my parents and friends saw me as an ordinary girl, I really wasn't.

The more I noticed other children whispering about me, the more uncomfortable I began to feel in my own skin. As I grew older, I maintained the belief that I could do anything, but I also became more aware of my physical differences. I more often witnessed strangers assessing my facial abnormality. I couldn't deny it any longer. I looked different, and my spirit broke whenever somebody else pointed that out.

One day in middle school, I sat at the mall food court with a friend. A woman came up to us as we ate our Chinese food, looked me straight in the eyes, and proclaimed, "Jesus loves you." Then she disappeared as quickly as she came. She never acknowledged my friend, never said, "Hello" or "Have a nice day." She simply ruined my meal with a solitary phrase. Apparently she felt I needed to know that the Lord still loved me even with my imperfections, which gave me no comfort at all.

Let me say this to anyone who agrees with this woman's actions: Singling someone out because of her uniqueness, even if doing so is well intended, is not an appropriate act. It does not promote self-love and acceptance; instead, it fosters feelings of self-doubt and isolation. Having a stranger single me out in a crowded establishment made me even more aware of my flaws. It was like tunnel vision. When she spoke, it was only she and I in that moment. The world around me had faded to black, and her eyes bore into me.

That occurrence, that single phrase, scarred me. It serves as a reminder that some people will always see me as flawed or damaged. Or perhaps, it's something deeper. Maybe it's a reminder that *I* will always see myself as flawed or damaged.

That woman may have thought her words were somehow intended to help, but in truth, they ruined my day. They made

me only more acutely aware that my appearance differed from everyone else's. I was left feeling distraught and hurt. When I hear that phrase now, my heart drops. Twenty years later, it conjures up the same sensitive response I had when I was a child. My inner self wants to leap out of my body and hide in the darkness for days, to suffer in silence because no one else can appreciate how I grieve from the emotional distress caused by those three, small, otherwise benign words. I experience such a feeling of immense isolation whenever I hear them: *Jesus. Loves. You.* A simple smile from the woman would have sufficed. A smile warms my soul. It communicates love and open-mindedness. I would have accepted a smile with open arms.

By the time I reached high school, I had been fully aware of my facial anomaly for years. I still didn't let my awareness hinder my daily activities. I continued to take advantage of every opportunity that presented itself just as I was taught to do. I played soccer with the city league, I joined various clubs at school, and I maintained a high grade-point average; however, I could no longer outrun the feelings of inadequacy building up inside me. Even if I saw myself as ordinary, I recognized that this might not be evident to strangers at first glance.

I volunteered a lot in high school. One year I decided to devote my time to the Special Olympics. I figured this was a large organization, and they would put on an amazing event for the athletes. My grandparents drove me forty-five minutes to the high school where the games were being held. Back then, I often felt a bit anxious around new people and being in new situations. I could never guess how strangers would react to me.

The high school was bustling with activity. I walked up to the

information desk to check in for my shift, but before I could utter a single word, the volunteer asked if I was there to participate. I understood and appreciated her misapprehension about my presence there. I hadn't yet undergone the most significant of my facial surgeries. I looked different from other people, so she assumed I must have been a participant. It wasn't malicious. It wasn't meant to offend me. It was simply ignorance in its true form.

Most people don't know how to act when they approach unfamiliar scenarios, or in the case of that woman, unfamiliar syndromes. Had the volunteer simply asked, "How can I help you?" I wouldn't have dreaded the volunteer work I did that day, standing on the sideline of the basketball court my entire shift. I was so terrified that at any given moment someone might pull me onto the court to participate in the game that I forgot the real reason I was there: to help others.

I wish I had enjoyed my time there, but instead I vowed never to return. I felt like I was the sucker at the end of a punch, like my breath had been forced from my lungs. I much preferred to live in the fantasy world where the girl I saw in my dreams mirrored the girl I saw in my reflection. I hated realizing that outsiders didn't see me the same way. My experience with the Special Olympics taught me that, whether warranted or not, I would always feel judged on my looks. But it also reinforced that I had to do everything within my power to make people focus on my accomplishments rather than on my appearance. I had to show the world that my abilities were unlimited. My biggest motivation for success therefore became the desire to break down the barriers erected by others, and my closest ally became my strength.

Strength Prevails

Immediately after my first major facial reconstructive surgery, I developed certain behavioral problems that I had not exhibited earlier; I was afraid to be alone at night, I didn't eat much, and I became very quiet. No doubt the trauma of that event affected me to a degree. But as the days and weeks went by, I became my old self again, and soon I was back to normal. It seemed that even at a very young age I was able to bounce back from adversity.

We all face adversity at one point or another, but for some people that adversity is an ongoing struggle. How we react to our challenges in life defines us. Some people succumb to adversity; others persevere. Even as a young girl, I chose to attack my problems forcefully, head-on. I vowed to turn obstacles that stood in my way into inconveniences I could push aside. To do that, I knew I would need all the strength I could muster, but I was certain I could do it.

Strength became my closest ally, my most revered friend, my lifeline to safety and self-assuredness. With it, I constantly sought ways to break through seemingly impenetrable barriers. Whether mental, emotional, or physical, my strength became my greatest personal attribute. That quality became the best-known part of my personality, one that everyone soon recognized as distinctly me, and one I did not try to hide. Strength became my brand, and it served me well during the most difficult times of my life.

Throughout all of my hospital visits, nurses would comment on my mental toughness as they gazed upon my misshapen, bruised, and battered face. Though most patients in my condition needed morphine to deal with their pain during the recovery process, I

refused it on most occasions. I suppose my nurses didn't often encounter a patient, battered beyond belief, who declined morphine the way I did, but that was my choice. However, I didn't refuse pain medicine because I was a masochist; I refused it because I did not want pain to defeat me. Asking for morphine seemed to me to be a sign of weakness, an admission that I couldn't take it, a confirmation that my surgeries were breaking me. I felt that if I couldn't take pain on that occasion, I might be weak on other occasions as well, even outside the hospital setting. I had to stay true to myself. It was the only way I knew to handle my life.

People often have said that my ability to deal with pain makes me appear cold and indifferent at times, that I don't show a lot of emotion. In actuality that is not the case at all; the opposite is true. I hate pain, I am terrified of pain, and I try to avoid pain whenever possible. But what others need to understand is that for people like me, pain, whether physical or emotional, is a way of life. It is an everyday, every-hour, every-minute occurrence. If I let every instance of pain get to me, I'd be in tears all day long. I can't afford to do that, even though sometimes I feel as though I'd like to have a good cry. So the way I deal with pain is to make it my enemy, to fight it, to not let it rule my life. It's not a perfect existence, but it works for me.

Over the years, as more and more people complimented me on my fortitude, my reliance on that trait increased. I clung to it as if my life depended on it. And it did.

To most people who met me, I seemed to navigate through life with ease, unaffected by my syndrome. That's because I exuded confidence. As a child, I made sure I stood up tall, I looked others directly in the eye when I spoke to them, and I never showed any

outward signs of distress when other children paid unnecessary attention to me. In fact, when I was out with my friends, I made it a point to appear as though I never noticed the stares of insensitive children when they gaped at me. I looked beyond them rather than at them. In reality, however, those stares bothered me. Every lingering gaze cut through me like a dagger. I wanted to snap my fingers and become invisible so I could make the humiliation stop. But I needed to remain strong and not show my vulnerabilities to my friends if I wanted them to respect me for who I was. I did everything I could to remain stoic and not give in to the emotions I felt.

When I was alone, however, and I caught children staring at my face, I reacted differently. It was always in one of four ways: I would let them stare and simply pretend not to notice; I would stare directly back at them until they averted their gaze; I would lash out with some rude remark; or I would smile. When I pretended not to notice, I made it seem as if I just wasn't paying attention and avoided the situation all together. When I stared directly back at them, I showed them how uncomfortable it felt. When I singled them out with snarky comments such as, "Can I help you?", "Do you have a staring problem?", or "Take a picture. It lasts longer," I admitted that their staring bothered me. But when I smiled, I almost always received a smile in return. It seemed, therefore, that smiling offered me the best approach when dealing with these situations, and yet, on occasion, I responded negatively. It was just so difficult not to get emotional once in a while.

Throughout the years, I have learned how to deal with weaknesses that affected my life. Vulnerabilities could lead to downfalls, and the last thing I wanted was to lose control of my life,

especially if it was obvious to others. I know that sounds petty, particularly for someone who has a lot of issues to deal with, but I have always felt it was important to keep my weaknesses hidden from other people. For this reason, I developed a stoic personality. It has served to keep my vulnerabilities hidden from outsiders, my deepest emotions reachable only by me.

My personal battle to succeed in life is mine and no one else's. Stoicism has allowed me to gain control of my life, especially when dealing with callousness from others. I have never been immune to hurtful words or actions. I feel everything deeply, sometimes too deeply. From my perspective, however, if I don't show that I am affected by those insults, then no one will know how much they really hurt. If I hadn't set up these protective barriers around myself at an early age, I would have rendered myself defenseless, making me an easy target for harassment. And so through the years, a protective wall was slowly erected around my heart. I felt all ranges of emotions but never showed them. Even when I wanted to cry—when I should have cried—I kept the hurt bottled up. When necessary, I would simply walk away and find a place where I could be left alone to concentrate on whatever it was that bothered me.

Some people may feel that by not expressing my negative emotions, I'm somehow ignoring my inner turmoil; that by putting on too strong of a front, I'm in fact weak. I think of it this way: I want my hallmark to be my strength and my positivity. When people get to know me, they realize that even in adversity I find a way to persevere. They admire my unbreakable spirit and how ready I am to always face challenges. They're impressed that I don't show my wounded side after everything I've been through. They

don't pity me because of my deformity. They respect me for my resilience.

My emotional strength has allowed to me live an ordinary life. But that attitude has been greatly enhanced by another asset I possess, which has done more for my confidence than perhaps anything else that has ever touched me, and that is my athletic ability. More than any other attribute I may possess, I believe it is my physical strength and abilities that have allowed me to live a life with endless possibilities.

When you live life without limitations, you rarely question whether anything can be possible; instead, you take the steps to make things possible. You achieve more because you're open to more. My door to possibility opened the moment I enrolled in gymnastics. I immediately felt drawn to athletics, though at the time I was unaware of the tremendous impact it would have on my life. The more I endured with my operations, the more I focused on becoming a stronger, more powerful athlete. I vowed that my physical strength would become my greatest tool for breaking down stereotypes. Gymnastics sat at the forefront of this mission.

My coaches treated me as equal to my peers right from the start. They would acknowledge my recent surgeries but push me to my limits nonetheless. They recognized my abilities and understood that I wouldn't have been allowed back to practice if my doctor didn't think my body could handle the hard work. When I wanted to slack off during sit-ups, my coaches encouraged me to reach the limit like the rest of the team. If they saw me struggling, they probably would have backed off, but they never had to. I kept up with my teammates because weakness wasn't a good look on me.

My athleticism was one of the ways I obtained the respect I

demanded. It's one of the reasons I led a bully-free life as a child. I was physically more capable than my classmates and made sure they knew it. I always pushed myself to do the most pull-ups during the annual physical fitness tests, even surpassing the boys. I wouldn't stop at the minimum requirement to earn the highest-ranking patch. I had to crush everyone else. Why? Simply because I could. By doing so, I stated a point: Respect me.

My strength commanded attention. I was thought of as the girl to beat, not the girl with a weird face. I was the girl who did "ninjas" (back handsprings), not the girl who had surgeries.

I was Kristin, not Treacher Collins.

Athletics gave me a chance to shine my brightest and prove my greatness. It emphasized strength while nurturing the competitive spirit. It solidly displayed my abilities to anyone watching. I began to crave the physicality of sports. Athletics demanded attention by being visible and tangible, while art and intelligence focused more on quiet, personal goals. Sports always appeared more boisterous, and that in-your-face, obnoxious attitude was exactly how I planned to be noticed. I needed something physically challenging to overshadow my physical flaws.

When I joined the competition team in gymnastics, I initially offered sub-par performances and won only two ninth-place ribbons throughout the entire season. My parents hadn't realized that the summer prior to competition season, I should have been practicing gymnastics. Instead they enrolled me in computer camp with the rest of my school friends.

The following summer, my will to succeed led me to spend every waking hour at the gym. I trained privately with my coaches to perfect my weakest skills and practiced on my own even when I

didn't have to. My muscles grew stronger and the skills became easier. I repeated level four, the introductory phase in competitive gymnastics, and effortlessly won most of my competitions, thanks to the excessive training I forced upon my nine-year-old body. During competitions, parents from opposing teams were often overheard discussing the unfair advantage my team gained by having held me back for another year. It seemed I had people right where I wanted them: discussing my superior skills and not my syndrome.

During the final meet of level four, I achieved a victory that was a first in the state of Florida (or so I was told). I received a perfect score, a perfect ten. This meant I had performed my floor routine flawlessly without a single flexed foot, bobble, or bent knee. It's a near impossible feat to be perfect in anything, but I, a girl full of flaws, achieved perfection before anyone else. I tore down any lingering barriers between judgment and reality that day.

Even in that time of tremendous triumph, my stoicism held the reins. As the scoreboard turned toward the audience, a thunderous reaction came from the crowd, drowning out every other sound in the gymnasium. My coach thought the bleachers were caving in, but as the scoreboard turned to face my team, he realized the cause of the crowd's exhilaration. My team saw the perfect score and joined in the commotion as I sat there unfazed. I hugged my coaches and teammates, accepted their congratulations, and continued watching the other competitors as if nothing extraordinary had just happened. I was humbled yet simultaneously aware that I'd always considered perfection attainable. Of course I recognized the improbability, but I never doubted the possibility.

That meet, I won every single event in addition to the all-around

title. I didn't even bother returning to my seat in between the award presentations for the individual events. I wasn't arrogant; I was victorious. Being raised without limitations allowed me to push beyond any preconceived notions about a person with a physical anomaly—that I was weak, slow, stupid, or inconsequential. I was none of those things. I was raised to believe I could even defy gravity, and I accepted that challenge. I proved myself that day by winning five gold medals.

My total domination of the competition flattened critics, but the most impressive aspect of the day came with the realization that a girl with a hearing impairment earned a perfect score on the floor exercise, an event synchronized to music. This was the day that gymnasts, coaches, and judges from the state of Florida opened their minds to possibilities. I wasn't to be pitied for my syndrome. Despite wearing a hearing aid, I heard every single beat of the floor music and knew precisely how to execute each move. My perfection garnered lasting respect.

Gymnastics instilled in me a drive that I might not otherwise have known possible. It taught me to find an ally in my physical strength, to fight for what I wanted, and to prove that I have nothing holding me back. From that point forward, I may have been recognized for my face, but I was remembered for my talent.

I continued to navigate through gymnastics with grace, determination, and success. It became an outlet for aggression more than creativity by forcing me to push my body to extremes. To reach success, I had to push harder, fly higher, and run faster. I allowed any negativity to be my motivation, as if it were seeping through my veins and fueling my workouts. As we often heard in practice, pain was just the weakness leaving your body, and my

body wanted all of that toxic weakness to spew out of its pores like sweat.

Sometimes I think my coaches forgot just how motivated I was. And like a child too smart for the average class in school, I wouldn't reach my full potential unless someone recognized the need to push me further. The summer when I was twelve years old, the owner of my gym pulled a group of girls together to train with him as the next superstars in the making. I was the only one from my clique not invited into this group, which I found frustrating. Eventually, he included me, but to this day, I'm uncertain why he changed his mind and invited me to join his special group. Maybe he saw my potential; maybe he'd forgotten to include me in the first place; maybe he just felt sorry for leaving me out and invited me out of obligation. I didn't know then, and I'll never know now. I was the first gymnast he ever coached to a perfect score, yet I was the last person who came to mind as the next superstar.

Nonetheless, I spent my summer in daily ten-hour practices. The first four hours were dedicated to my special group for growing, strengthening, and prospering. Each morning, I learned how to become an even more effective gymnast by drawing from my strengths. We focused on endurance and conditioned our bodies to peak form. At the end of the summer, we were judged on our current routines to see just how the practices had affected us. When I performed on the uneven bars, I flawlessly hit moves most people missed. My routine earned a 9.7, a mere three-tenths of a point away from perfect, and the owner of the gym finally acknowledged I indeed belonged in his band of superstars. I never sought out his approval of my abilities. I knew all along I belonged on the short list of great gymnasts. I didn't train hard to please my coaches or

make my team's name synonymous with success; I trained hard to squash pity and win for myself.

I have been out of the gymnastics world now for more than twenty years, but I still find ways to prove my physical abilities. Currently, I've taken up an activity I never imagined I would even remotely enjoy: running. I have completed four marathons, numerous half-marathons, and a host of 10K races, with more on the horizon. My greatest achievement thus far is completing the Marine Corps Marathon in 2015 in honor of my grandfather.

My body has been the one constant in my life. Its physical strength allowed me to carry the weight of my world for thirty-three years and, at times, even helped me forget my syndrome. When I was younger, I spent time at water parks, and on numerous occasions the lifeguards questioned whether I was a gymnast. My muscles drew attention away from my face, away from the scars, and away from my hearing aid. In the years when my syndrome was much more pronounced than in the present, I craved that deflection of attention. My physical strength became the diversion I relied on to hold my self-confidence. While my surroundings, friends, and even face have changed over time, my body remains a steady source of personal gratification. By continuing to focus on that physical strength, I forget about the physical flaws caused by my Treacher Collins syndrome.

I continue to nurse the need to prove myself daily. It's that fight, that determination, that drives me. I shouldn't have to do this. I shouldn't have been forced to build a bubble of positivity around myself to banish the crippling opinions of outsiders. No one should face judgmental limitations. Just because I don't look the same as everyone else doesn't mean I'm not smart or creative or athletic.

No one ever told me to my face that I couldn't do something, but at times the implication lingered. Ignorance fueled my determination. I'm thankful for everyone who thought my Treacher Collins syndrome limited me; their doubts only made me stronger. Even if no one ever doubted my abilities and I imagined it all, I flourished thinking they did.

I once believed that God chose the strongest people to struggle because they would be the most likely to rise from the rubble relatively unscathed. As I grew older, and undoubtedly wiser, I realized that not everyone who struggles prospers. Strength couldn't possibly be a derivative of divine intervention when so many people succumb to their adversities. Those who embody great mental strength are not preselected in the womb to be born with such a trait; they make a conscious decision at some point in their lives to adopt that quality and build on it as they grow. A long time ago, I was in a position where I could choose a path of failure or a path of success. I chose to walk the line of success with unwavering courage, fierceness, and strength. And that has made all the difference.