“It’s Chyckxn!”
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The Unculinary Way
I Made Life Palatable

A Memoir
Christina Stramacchia
Underdeveloped facial features are some of the characteristics of Treacher Collins Syndrome. The seed of resilience that also accompanies the syndrome is not as noticeable unless it is cultivated and encouraged to flourish.

To my extraordinary parents who did just that.

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"It's Chyckxn!" The Unculinary Way I Made Life Palatable
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Dear Reader,

This is my story. It is one that very much reflects my life’s journey and my perspectives on the lessons I have taken from those experiences. My memories do not always follow a strict chronology. My diary entries at times proved to be a portal to experiences I had long forgotten. Many of the events I write about in this memoir happened simultaneously: working, going to school, having surgeries and dating. I have attempted to organize them in the most appropriate sequence possible.

Out of respect for the people who have been instrumental in my life, names and identities have been altered.

I share my experiences with the hope of cultivating an understanding; that what makes us different is in fact, what makes us uniquely beautiful. It is my hope that one day, society as a whole, is at a place where embracing diversity is an ordinary occurrence.

— Christina
“I’m not beautiful like you.
I’m beautiful like me.”
—Joydrop
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“Mom, what is this?” I asked as I poked at the breaded meat she had just put in the centre of the dinner table. “Because I don’t want it if it’s deer or moose meat ... it’s gross!” I reminded her for the umpteenth time as I pulled my fork away in disgust.

“Oh, Christina, just eat it! I’m sure I’d feed you poison!” she responded sarcastically, annoyed as she began to fill my younger brother Leo’s dinner plate.

 Hmm ... I’m going to err on the side of caution, I thought.

“I don’t want any,” I told her as she bent over to grab the plate sitting in front of me to serve it. She exhaled in frustration, as if she didn’t have the energy to have this argument with me yet again. I’m certain she gripped the serving fork just a tad tighter when she realized I wasn’t going to make this meal an easy one.

From the head of the table, my father picked up on his cue and chimed in. “Don’t be so silly, Chris. Eat it. It’s chicken!” he exclaimed in that tone only a father has that sends a clear message not to argue with him. “Is it, Mom?” I quickly lost my sass, pleading for an ally. He could be lying, I thought. He’s played this trick before.

“Yes, it’s chicken, Chris. Just eat it,” she said, corroborating my father’s explanation.

She placed a small piece of chicken on my plate and handed it to me. “Make sure you cut it up into small bites so you don’t choke. Or
give the plate to your dad and he will cut it up for you.” She motioned for the plate to be passed to my dad.

“I’ll cut it myself!” I protested, picking up my fork and knife and slowly dissecting the mystery meat. Out of the corner of my eye I could see my father had put his fork down and was watching me carefully, checking to make sure that I was cutting the meat into bird-sized pieces before putting them in my mouth.

Cutting my food up into tiny bites started when I was a child and has become a lifelong habit. With my abnormally underdeveloped jaw and my small, narrow airway, choking was common and one of my parents’ greatest fears. It’s still something I am aware of every time I eat. “Go slow,” I remind myself before embarking upon a meal. I looked around the table at all of them: Mom, Dad, my brothers Sal and Leo. No one was laughing, and no one was smirking; in fact, the boys were shovelling food into their mouths as if they were starving. It must be chicken, I thought. I took my first bite. Wow, this is good! Yup, it’s chicken, I concluded, and I happily ate my dinner. Years later, I realized it was not always chicken I was eating.

My father was a hard worker and a wonderful provider for our family. His passions were building, planting, and hunting. I had no issue with any of those passions, except for the last one. When hunting season began, Dad and his friends would pack up their trucks for a week-long hunting trip up north. They hunted deer, moose, and bear—whatever four-legged beast was in season. One of those creatures inevitably ended up on our dinner table in a variety of forms: stew, roast, or cutlets.

It wasn’t because I didn’t like the taste of wild game, because I never willingly tasted the meat. If, on the off chance, a piece managed to sneak under my radar and I did taste it, I’d quickly spit it into a napkin. My gag reflex was an added effect, making my dramatic performance worthy of an Oscar nomination.

I liked meat. That was not the issue. I just didn’t want to eat that kind of meat. My parents pleaded with me to take a bite and tried convincing me that it wasn’t so bad. “Look! Your brothers are eating it; they like it. You’re going to like it!” my mom would say. My father even tried his hand at reverse psychology. “If you like it, you’re not getting more.” Out of pure frustration, they even tried threatening me with “you’re not leaving the table until you try it.”

Eventually, when all their tactics caused more resistance, they stopped trying to coerce me. I was relieved. It became customary for me to question any type of meat that looked a bit different. More often than not, their response was that it was chicken, veal, or beef of some sort.

I was in my early teens when it dawned on me: we ate a lot of chicken at our house. My “ah-ha” moment came when I realized that my “chicken dinners” weren’t really all chicken dinners. For most of my childhood I thought I was eating chicken, and the odds were that I wasn’t. In fact, chances were it was everything BUT chicken. I was stunned by this realization, and mad! How could they? There was the notion of trickery and betrayal—a harsh word, I know—but I remember thinking, Why would they lie to me?

It wasn’t a harmful lie. In fact, it was quite the opposite; I was eating healthy, organic meat—hardly anything to call the authorities about. With some bread crumbs, some sauce, a sprinkle of garlic, and wouldn’t you know it, I loved chicken!
How does a seemingly common dinnertime experience become the title of a memoir, thirty-five years later, when the memoir is anything but common? I am the one in fifty thousand births that result in the syndrome called Treacher Collins (TCS). As my life unfolded, I learned I would always be the exception to the rule—the unlikely percentage of any odds. That is me. I am her. If there were a two to three percent chance of something happening, be assured I would be in that group.

I look different. The characteristics of TCS are not easy to hide, because I wear them on my face. Chances are you will probably look twice at me, and nine times out of ten you will silently ask yourself, What happened to her face? or worse: What’s WRONG with her face? What you see is underdeveloped cheekbones and downward-sloped eyes, a disproportionately small jaw, deformed ears, and wide nose. What you don’t see is a small airway, cleft palate, and cognitively normal brain and intellect. What some of you won’t see is the person I am, because your curiosity will keep you stuck at What happened to her face? Unfortunately, you will likely apply stereotypes to my situation in order for you to make sense of how I look and why. Some of you will make judgments about me based only on what you see. By the same token, you will also never know that at my house with my family and friends, I was treated as if I looked just as “normal” as you do. When I ventured outside my world within my home as a child, your stares confused me.

I thought almost everything about me was normal until the stares, whispering, and pointing of strangers made me feel isolated and alone. I calmed myself by silently affirming, reciting that I was okay because I had two eyes, a nose and a mouth, two legs and two arms. I told myself the only difference between me and everyone else was that I didn’t have ears, and I wore a hearing aid. Not a lot of people were born without ears, but some did wear hearing aids. It was okay that I didn’t look like everyone else; I had friends who wore hearing aids, and I was like them.

But when I was home, no one stared, no one pointed, and I was just a regular kid. The way the world saw me and the way I saw the world constantly clashed. When I was out in public—it didn’t matter

where: at church, the grocery store with my mom—there was always someone looking at me. When I sat in the backseat of the car, people looked at me as we waited at red lights. Inevitably, someone in the next car over would do a double take once they noticed me. Clearly I was not like everyone else. Occasionally, if there were an older kid in that car, that kid would point, stare, and sometimes laugh. I always got a churning sensation in my stomach (which I can now label as embarrassment and shame).

Sometimes I wanted to hide, but there was nowhere to hide in the backseat. Sometimes I made faces back at them, and other times I would just pretend I was asleep. It wasn’t until I was well into adulthood that I finally conquered the anxiety of traffic jams.

I never told anyone about these experiences when they were happening; it never seemed like the “right thing to do.” The less people knew of my embarrassment, the better. Maybe it will go away... Shame, I have come to learn, obtains its power from its ability to make us feel alone—as if we are different from everyone else. Hindsight tells me that maybe if I had told someone, they would have explained that what I was feeling was anxiety, and they could have taught me how to cope with it. But I didn’t speak up. Instead, I tried to ignore it until I was safely at home, where I felt confident and normal. No one pointed, stared, or laughed at me—unless I had made a joke.

As young as six or seven, I would take notice when adults or children looked at me for a little too long. When I became bold enough to stare back at the adults, they would quickly turn away. They’d pretend they didn’t see me and then try to look at me out of the corner of their eye without turning their heads. I couldn’t understand why
they were staring at me and why they didn't just smile at me like they did when they looked at my brothers. I didn't think I was THAT different. I mean, after all, it's just a hearing aid. There were occasions when someone did not look away. They'd smile. But even their smile was an awkward one that never left me with the warm, welcoming feeling that smiles usually do. Instead I felt shame, and I would quickly look away. I never knew why I felt this way — I hadn't done anything to warrant the feeling. It was always very confusing.

Young children have always been less polite; they just flat-out stare. They'd often point and ask their mother, “What's wrong with her?” At one point during my youth, I had found a positive in those encounters — at least they could tell I was a girl.

The reoccurring question in my mind throughout my childhood was always, why are people looking at me? I cannot recall my parents or family ever talking to me about looking different or having Treacher Collins unless they had to because of a pending surgery or if I asked a related question. My parents would try to protect me from the stares of strangers by distracting me and ignoring the stares themselves. Sometimes they would get mad and glare back at the strangers, and sometimes they would even make a stern comment. I liked when my parents did that because I felt like we were on the same team, and at times I felt guilty because I was causing their upset. We never talked about any of these situations at home. Instead, we just went on pretending they never happened and that they never affected me beyond the moment they occurred. I tried to convince myself that looking a little bit different because of deformed ears and wearing a hearing aid was not a big deal. I learned to ignore uncomfortable feelings and pretend they did not exist. But the older I got, the stares from strangers — the ones I was supposed to ignore — told me it was a much bigger deal than my family let on.

In my preteen years I became well aware that I was different in more ways than just my "Muppet ears" and hearing aid. "Muppet ears" was the age-appropriate description my mom coined to explain my underdeveloped ears to me. My mom never referred to my TCS traits as deformed. If she didn't give it a playful nickname, she just described the characteristics, like sad-shaped eyes. The Muppet ears were thick skin tags in the place where natural ears would be on someone who didn't have the syndrome.

The challenge became reconciling my perception of how different I was with society's perception of the depth of my difference. Adolescence is naturally an awkward stage; I just did not know if my awkwardness was the same as everyone else's adolescent awkwardness. My childhood confidence seemed to have melted. I began to look away before a stranger saw me so I wouldn't have to see that stupid blank stare or forced smile they offer. I also looked away to avoid seeing how embarrassed they were if their child asked questions or stared at me a little too long. Sometimes I looked away for my own sake, but most times it was for everyone else's.

By the time I was an adult I was skilled at identifying a genuine smile or the "poor thing" smile. I could spot the latter in an instant. I have seen it more often than not, and the accompanying annoyance that it provokes leaves me shaking my head in disgust. It's the pressed lips, straight-line smile, and slightly tilted head posture. The stranger's eyes would dart from me to somewhere else— anywhere else — but not for long, because they were immediately back on me again. Like a moth to a flame, they couldn't not look at me.

In my adulthood I secretly began liking the post-surgical affects of the swelling, because it filled in my sunken cheeks and made it look like I had cheekbones after my surgeries. I remember loving how my face rounded from the swelling and wishing it would stay like that. When people stared at me post-surgery, I knew they were staring at the swelling and bruising. It actually made me less anxious because they were staring at an injury and not at me.

With time, I learned to judge a successful surgery by the look on complete strangers' faces when they saw me after the bruises had faded and swelling subsided — children in particular. It's an age-old concept, but it's so true: if you want to know the truth, ask a child. I didn't ask, I simply watched. Did they stare? Did they ask questions? Did their mothers block their eyes and turn them around for fear that their child might say something offensive and cause them to question
Chapter 1

That Was Not Part of My Plan

The oldest and strongest emotion of mankind is fear, and the oldest and strongest kind of fear is fear of the unknown.
—H.P. Lovecraft

Why do you hate me?” I screamed at the hourglass on the computer monitor in front of me as I gripped the mouse a little tighter and restrained myself from slamming it on my desk! “I just want to save the report... please!” I said to the screen as the hourglass ignored my plea for mercy with the Word document frozen on Not Responding. My mind quickly reverted from the frozen screen back to the frustration from which I had spent the majority of the day trying to distract myself. I did my best to focus at work, believing that the more I threw myself into paperwork, the less anxious I would feel. The constant swirl of anticipation and hope kept me on the edge of my seat all day. What do those results say? Did we actually find the genetic link? More importantly, am I going to be able to move forward with this decision?

A few years before, I had been tested for the more common gene associated with Treacher Collins (TCOF1), without success. Today my boyfriend Nick and I were going to learn the results of the subsequent genetic testing I had undergone to determine if I had the two new additional genes that were discovered to be related to Treacher Collins Syndrome.

Every so often I'd glance at the bottom right-hand corner of my computer screen, willing the clock to be 5:00 p.m. Of course, the minutes crawled. Our appointment with Dr. Greer was scheduled for right after work—5:15. The appointment time was carefully organized so
Nick, my mother, and I could all be there. My dad was supposed to attend as well. For some reason Dr. Greer specifically requested that he be in attendance. Unfortunately, my dad was out of town at the time and unable to make it.

Nick and I had been together for quite some time before we seriously began discussing starting a family. I was both excited and tormented by the topic. The prospect of passing Treacher Collins on to my children weighed heavily on me. If we decided to have a child, there was a fifty percent chance it would inherit this dominant gene. Was he prepared for that? Was I?

I’m here, said the text from Nick at exactly 5:00 p.m. I shut down my office computer, grabbed my purse, and raced out the door to his waiting truck. Hopping in, I shook off the raindrops and leaned over for a quick kiss. I noticed he’d gone home to change before coming to pick me up; he wasn’t wearing his construction gear, and I could actually smell his cologne. At six foot four with a football player’s physique, he was such a handsome man. His blueberry-blue eyes were supported by high cheekbones, and beautiful, full lips were guarded by a neatly trimmed salt-and-pepper goatee. He had a defined jaw that I was envious of and the most perfect little nose. His crooked tooth was my favourite. He was self-conscious about it, but I loved how it made his smile mischievous in an instant.

“How was work, Pie?” he asked lovingly as I turned to pull the seatbelt over my shoulder. I still melt every time he calls me “Pie”; it never gets old, and it’s a constant reminder of his playful demeanour. “Pie” is derived from Nick’s nickname for me; “Pisano”.

“Not bad. I spent most of the day trying to distract myself from thinking about this appointment, so I’m glad it’s finally here.”

“You nervous?” He smiled; he knew I had been anticipating these results for weeks.

“Anxious, really. I’m excited too. Because if the results are what I’m hoping for, it will be a huge relief because we will have more options.”

“Doesn’t matter to me either way, Pie,” he said as if he was talking about the weather.

He has no idea what he’s saying, I thought, instantly irritated. I turned to stare out the window and focused my energy on keeping the overwhelming sense of anger creeping up on me to stay away.

Nick had known about Treacher Collins Syndrome from the onset. It was kind of hard to miss; the distinct characteristics were all over my face. By the time we met, I had a strategy and a polished script I used to explain Treacher Collins as an intimate relationship developed. I had a couple trial runs with it, and so far it was successful. But this was a different level of discussion. It was not about how Treacher Collins affected me but how it could possibly affect our children. Now it hung in the air like a big fat question mark. The prospect of passing the Treacher Collins gene onto our child was not a topic Nick ever brought up during any of our conversations; it was a topic I brought up. No need to avoid the pink elephant in the room. It was important to me that we both knew exactly what each other’s cards were, and those cards had to be laid on the table. I needed to know what I was “signing up” for, and so did he. No sneak attacks. Eyes wide open. No grounds for leaving the relationship with a “you didn’t tell me that because I wouldn’t have signed up for it!” excuse. In my mind he could leave the relationship for whatever reasons, but “not knowing” and “you didn’t tell me” would never be acceptable.

During our conversations about marriage and children, I let Nick know the results from the initial genetic testing with the geneticist, Dr. Greer, in 2006. The results indicated that I did not have the identified gene (TCOF1), for Treacher Collins Syndrome. Afraid he was missing the point, I explained that this did not mean I did not have the gene; it simply meant science could not yet locate my particular Treacher Collins gene. The concept of having a family with my own biological children was/is a crapshoot for me, in terms of passing on the Treacher Collins gene.

His response still made me smile. “You turned out alright, Pisano. I can handle that.” I began to love him a little bit more from that point forward.

Since it was raining, Nick dropped me off at the door while he parked the truck. Just as I hopped out, my mother rounded the corner with her umbrella. The woman had impeccable timing. Under her
shared umbrella, we chatted about our day as we made our way up the stone walkway to the health clinic doors. During the testing for these two new Treacher Collins-associated genes, a variance was discovered. Dr. Greer’s nurse had called several weeks ago with this news and requested that both my parents submit a sample of their blood in order to be tested for the POLR1C and POLR1D gene as well. Excited at the possibility that this might be the missing link for me, my parents complied immediately when I informed them of the possible linkage of the variance with the syndrome. Dr. Greer’s office called once the results were in and summoned not only me but my parents as well—specifically my father—to the follow-up appointment. While I had Dr. Greer’s nurse Amanda on the phone, I probed just enough for her to give me a little bit of a heads-up as to what the results might be and why Dr. Greer put such an emphasis on my father attending. She finally said that there appeared to be a variance match on both mine and my father’s DNA when they did the POLR1D test. Dr. Greer wanted to see my father to determine if he had any mild Treacher Collins features.

When my name was finally called, Nick, myself, and my mother stumbled into the very small examining room, which instantly became a sauna. My mom and I took the seat directly across from the desk, and Nick plopped himself down in an empty chair along the wall. This dynamic bothered me. If Nick was supposed to be my partner and this appointment was about “us” and our family, why did he choose the spectator’s seat along the wall and let my mother take the supportive role? Or was I overanalyzing again? It was only moments later when the resident doctor walked in behind us with a swift hello, that my attention was diverted. As he sat down in the doctor’s chair, he started to review my chart. Straining to see what was in the file, I noticed him eyeing my family tree on a piece of paper. Dr. Greer’s nurse, Amanda, and I had constructed that family tree in 2006 when I was first exploring Treacher Collins. Watching him, I wondered whether he was going to examine the entire file in silence or whether he was going to tell us where Dr. Greer was.

As I was sizing up his rudeness, he tore his eyes from my chart and smiled at me before asking the dumbest question. “Christina, I’m Dr. Greer’s resident, Dr. Michael Ottoman. I just want to go over a few things with you before Dr. Greer comes in. First, do you know why you are here?”

Already annoyed, I glanced at Nick with a less than impressed extra-long stare. I wanted his camaraderie on this. Instead, I caught his smirk as he put his head down, deliberately avoiding eye contact with me. This told me that he knew I did not take lightly the doctor’s patronizing tone. Insulting my intelligence was not a good way to build rapport with me. I looked back at Dr. Ottoman and allowed my internal filter to offer me some guidance. I told myself (as I have many times over the years) to relax and remember that the resident doctor was learning and that the question he posed must be part of a script he read for bedside manner. Or maybe he wants to make sure you are coherent, Chris. Isn’t that what medical staff asks a person when they have a concussion? Do you know what day it is today? Same thing, the voice of my sarcasm pointed out. I bit my lip to prevent my sarcasm from spilling out. Unfortunately, I couldn’t restrain my eyeballs and gave him a look that clearly questioned his intelligence.

“Yes, I’m aware of why I’m here. Will Dr. Greer be in with the results soon?” I responded with enough sass to let him know his condescending tone was not lost on me.

“Momentarily,” he answered, returning his eyes to my chart, unfazed.

However, before he could formulate a question that wouldn’t elicit eye-rolling from me, the door to this very small, hot room opened as Dr. Greer made his appearance. With a big, bright, welcoming smile, he walked toward me with an extended hand. It had been a number of years since our first meeting when I began my initial quest to find the Treacher Collins gene in my DNA. I felt comfortable with him; on some level he understood me—well, my genetics, anyway. There was no “fixing” involved in our relationship. He wasn’t going to operate or reconstruct anything. He was simply going to help me discover if I had an identified Treacher Collins gene.

Dr. Greer immediately welcomed me like an old friend. After we exchanged pleasantries, I introduced him to my entourage. I took the opportunity to explain that my father could not join us for the results. Although disappointed, Dr. Greer was content with reviewing the
The presence of that unknown question of whether my baby would resent me for passing on Treacher Collins weighed heavily on my mind long after that conversation. I tried to focus on other tasks that needed attention. Somehow, though, like a nagging toothache that just wouldn’t go away, it always managed to creep to the forefront of my mind, especially whenever I heard a pregnancy announcement or saw a young mom with a baby in tow. Or when my sister-in-law announced her second, third, and fourth pregnancies. It was like everyone’s life kept moving forward, and I was still stuck at deciding. The question mark was like that one folder that sat in the to-be-filed bin on top of my filing cabinet for months on end. Instead of sorting through that folder and finding a place for it, I kept putting it back every month because I couldn’t be bothered to find the category it belonged under. Month after month it became a nuisance. Its constant presence demanded attention, and it would not go away or find its own place until I did something about it.

And then there it was. One day I was doing what I always did when I was feeling overwhelmed and perplexed with life: cleaning out my closet. When I needed to have a sense of control over my life, I organized and cleaned anything I could get my hands on: a dresser, nightstand, cabinet, closet, all the while listening to some really loud music. On this day, as I tore clothes off hangers to throw into piles and tossed out shoes and boots to purge and organize, I found a large, circular decorative hat box with the Eiffel Tower on it that I had not opened since I moved into this house. As soon as I spotted the box, I remembered what precious mementoes of my life it held. I smiled warmly as I lifted the lid, revealing my neatly packed collection of diaries from my childhood well into my adulthood — all seven of them. I felt as if I was being reunited with a friend I had not seen in a long, long time. Sitting on the bedroom floor, surrounded by piles of shoes and boots and clothes thrown everywhere, and I began to read bits and pieces of the entries, flipping through this girl’s life, nodding in remembrance as the memories came flooding back and I related to her.

I was able to laugh and cry at my eight-year-old self with each entry. With every page, I reconnected a little bit more with this forgotten soul. I was not strolling down memory lane long before I realized I was turning to the only person I COULD turn to in order to make my decision to have a biological child: myself and my documented journey. My mom gave me my first diary, plush red velvet cloth with a diamond pattern etched over the cover; it was really quite pretty. The first entry was dated November 1982. I was eight years old. September of 1982 was when my paternal grandfather passed away from cancer, the entry reminded me.

I’m not sure if it was my questions about death that prompted my mom to introduce me to journaling, or if she just figured it was a perfect way for her daughter to express her grief. Looking back now, it seems logical that the diary was given as a tool to process difficult feelings; we were a family of few emotional words. This was a great way to keep the Chyckxn façade going. I would just write about my thoughts and feelings and not speak of them.

As I turned the pages of my diaries, I marvelled at my childhood writing on each page, in awe and oh so thankful that my obsessive compulsiveness had compelled me to hang on to them for all those years. I spent the next few days flipping through all seven of them, in
Chapter 2

Searching for a Needle in a Haystack

“Strong women wear their pain like stilettos. No matter how much it hurts, all you see is the beauty of it.”
—Author Unknown

In 2006 I was thirty-two years old, and I felt like I was on top of my game. So far I had been able to accomplish a few goals and kick over a few boxes. Hell, I may even have set a few on fire. I was proud of my academic success, grateful for my career, and appreciative of my place in life. As is true for many people, I could not have done it without the nurturing support of my family and friends. Yet despite all of this, there was a piece of the “normal” puzzle that I was missing. My biological clock was ticking. LOUDLY. I did my best to skirt around it; I pretended I was content with my life as it was. I struggled until I could no longer avoid the elephant (or the Chyckxn) in the room.

A large part of the void was a result of not being involved in a serious relationship. My mind was in a constant state of debate — it’s a wonder I slept at all. With my clock ticking, panic set in. How was I going to have a baby without a partner? My dreams of having a family came to a screeching halt the year before when my relationship with Gabe ended. It was a difficult break-up for me, to say the least, yet a necessary life lesson. Hindsight was 20/20, of course. At thirty-two, I was supposed to have married him, we were supposed to have kids and live happily ever after, thus showing the world (or maybe myself?) that I could do it all despite the limitations and confines that society places on those who look different. It was a head-on crash when that
relationship ended, and I was devastated. I was convinced that no one would love me and I was destined to live alone.

I wavered between wanting a partner and child and fantasizing about what it would be like to stay single. Maybe I just think I want a partner and kids, I told myself. Maybe I just want them because I’m supposed to want them. I’m a woman, after all. Maybe it’s the validation I need to feel complete as a woman, I rationalized. Does it just seem like the thing to do? Everyone else has kids … you should have them too. Kinda like keeping up with the Joneses. It will be great for the image of being normal, I justified. I mean, you’ll have conversations with other moms that will be relatable. You could talk about sleepless nights or debate what school curriculum is better or how the soccer coach was not being fair.

Maybe you don’t have the innate yearning to be a mother. Maybe what is at work here is your need to prove that you can live up to societal expectations. Being single would not be so bad either—you could move up the corporate ladder, and you could definitely travel more. Maybe you could prove your worth that way. Except no one in my family is single. Everyone gets married, “for better or for worse.” I pushed that thought aside and continued to elaborate on my plan. Maybe I could do it all, be a single mom and climb the ranks, two out of three ain’t bad.

But then on the left side of the debate came the question: How awesome of a life would it be to be in a loving relationship and create a living being with someone. Together, nurture and love that being into something magnificent? To create a being that is a piece of both of you? That sounds pretty damn phenomenal.

I come from a tight-knit European Catholic family. I grew up with siblings, a lot of cousins, aunts, uncles, and grandparents. We fought with each other and loved each other fiercely. I had a lot of family around me all the time (most of my family lived in a one-block radius), and I knew I was loved. Our traditions and rituals always included family. We shared all of our holidays, and found excuses to celebrate everything from birthdays to simple Sunday afternoons.

Watching friends and family celebrate the births of their children, the excitement at baby showers, the pictures of ultrasounds posted on refrigerator doors, the conversations about how the baby’s parents were hoping that he would inherit Mom’s thick hair and Daddy’s blue eyes.

All the excitement around a pregnancy announcement was contagious—until the thought of my fifty percent chance of passing on Treacher Collins clouded over the innocence of my thought.

These thoughts were a private reality for me. Contemplating motherhood involved more than simply trying to figure out daycare options for when I returned to work after the maternity leave was over. I imagined the decision for normal people to have a child did not include an evaluation of one’s DNA for a rare genetic disorder that could potentially set their child up for a lifetime of physical and emotional struggles, but it did weigh heavily on mine. I saw this decision to have a child and pass this gene forward as a large responsibility. There was not any one person who I felt would be able to explore this topic with me without them saying what they thought was the “polite, right thing” to say. I knew of no one who had knowingly passed on a genetic syndrome that I could talk to about the decision. Instead, I just smiled and pretended I was just like everyone else, expecting and fantasizing about nothing short of having the perfect child one day.

The making of history started with me. Does it end with me as well? The reality was if I had children, I was responsible for potentially passing on this gene for generations to come. A hundred years on when someone from my future lineage decided to do the family tree, would that novice genealogist point to my picture and say accusingly, “It started with HER! This was all her fault!” Or would she say in a nice, soft, inquisitive tone as she chewed on the stem of her eyeglasses, “Oh there it is. It looks like it started in 1974 with Christina; she’s the one . . .”

I rattled these thoughts and more around in my head until I finally decided the only way I would be able to make any headway on this decision was to begin investigating what was available in terms of genetic detection. I wanted to make the most informed decision possible. I wanted to know if and how I could avoid passing the Treacher Collins gene on to my child, and what options were available to me, regardless if I wanted to be a single mother or not.

When I began researching Treacher Collins, the Internet did not offer much—illuminating the rarity of the syndrome. At the time there were no Facebook support groups, and blogs were limited to barely a
handful. But what I did find was pictures of other people with Treacher Collins. I finally was able to see what I looked like. I finally saw Treacher Collins on someone else’s face.

The more I researched, the clearer it became that I was way out of my league trying to understand the information. The whole genetics-DNA-science thing was way beyond my comprehension. I tried desperately to dissect the scholarly journal articles I found online, and I quickly became exhausted trying to sound out twenty-syllable words. When I was able to somewhat pronounce them, it did not matter because I had no idea what they meant anyway! Exhausted, I concluded that WebMD and Google weren’t going to give me the definitive answers I needed. What I needed was concrete, specifically tailored information customized to me and my situation. However, what I did learn from Google was that the TCOF1 gene mutations were the most common cause of the disorder, accounting for eighty-one to ninety-three percent of all cases. I also learned that several options were available if the Treacher Collins Syndrome gene could be isolated in my own DNA. This was exciting news! And I took it straight to my family doctor, who promptly sent me for blood work and for genetic counselling.

During the limbo period between my referral and waiting for a consultation appointment, I went about my ordinary life. It was then that I was sitting in the dentist’s office when I stumbled on a magazine headline titled “Designer Babies.” The very enticing title worked, and I picked up the magazine. C’mon, would people really do that? Had society really become that shallow? It sounded like a modern-day Dictator to me. These people were talking about hair and eye colour! As I read the article, I compared it to my own situation; I didn’t think I was asking too much. I wanted to be able to test a few eggs and freeze the ones that didn’t have the Treacher Collins Syndrome gene. Did that make me a bad person? Would someone accuse me of trying to play God? Isn’t every child’s birth a blessing that we should not question? My Catholic guilt was setting in, and I began to think I had no business exploring scientific options. Was I taking my control issues too far?

Thankfully, my appointment with the geneticist came right in the nick of time. My first appointment with Dr. Greer was an enlightening and hopeful meeting. It was my lunch hour on a beautiful summer afternoon when I walked to the clinic, just blocks away from my office, filled with excitement and wonderment. I had no idea how to prepare myself mentally for the appointment. I knew nothing about my genetics. I looked like no one in my family, and for years that bothered me. Sure, my mom will tell you I have my father’s thick hair and her brittle nails, but I didn’t LOOK like anyone, anywhere in our family ancestry. People never said, “Oh she looks just like her mom (dad) . . .”

I remember incessantly asking my mother when we were at a hospital check-up at Sick Kids, “What do I look like, Mom? Show me.” She would point out a child with a TCS feature. “See, Chris, look at that little guy’s jaw, notice how it goes downward and he has a tiny chin? That’s Treacher Collins.” And I would stare at the kid, trying desperately to see what she was describing. Or another time she would point out, “See how her eyes shape downward like she may be sad . . . that’s what your eyes look like, just sad, that’s all.” I would notice because she pointed it out, and I’d think, Big deal, sad eyes! Hardly something to stare at someone for!

Dr. Greer was young, energetic, and short. He immediately made me feel comfortable. He talked about Treacher Collins with such ease, it was as if he was talking about the weather and not a rare genetic disorder that showed up in one out of fifty thousand births. I sat in his office, listening intently while he revealed the results. He looked at the paperwork in front of him then back at me. He removed his glasses and smiled. “I know, Christina, that you are aware ninety-three percent of patients with Treacher Collins Syndrome have the TCOF1 gene; however, these results indicate that you do not.”

For a brief second— and I do mean brief, because the committee in my head started yammering instantaneously upon hearing the results with a variety of opinions—I was relieved. That relief was accompanied by a voice that drew the seemingly logical conclusion: I don’t have the gene! So I can’t pass it on to my children! We are done here. Let’s go! Run! demanded the voice of my id. Despite the excitement and the command to bolt for the door, my body did not move. Somehow, I knew there was more to come. My life had taught me there was always a “ya, but . . .” not too far off.
As I thought about her downcast eyes in that picture, I was transported back to that moment. No one knew how sad that little girl was that day. They never did, because I’d learned how to be strong a long time before that. I was not even sure what “strong” meant, I just knew it had to do with not crying when I was going to Toronto for doctor’s appointments or surgeries. So whenever I felt sad about this, I knew I had to focus on not crying. Truth be told, that felt like I was holding my breath for an exorbitant amount of time. I did a good job too, because everyone always told me how strong I was. The story behind that picture was my mother and I were Toronto bound for a doctor’s appointment, and I did not want to go. I was not waving, and I did not want to make eye contact with my dad and Sal, who were seeing us off. The little girl in the picture couldn’t wave goodbye because she was making sure her “strong mask” was securely on. If she looked up, someone might notice she was holding back tears. What if she could not hold the tears back and the dam opened? Would everyone be disappointed that she wasn’t strong for real? That was not an option. I had to be strong, because everyone said I was. There were two sides to her: the happy, well-adjusted child was a good cover for the scared, vulnerable, sad child in the picture. I knew she didn’t really want to go, but she didn’t say that.

The word “Toronto” meant different things to each of us in our house. For my brothers it sometimes meant a possible vacation with a brief stop at the doctor for Chris. For me, I instinctively knew something dreadful was coming my way, and it inevitably involved doctors and hospitals. Going to Toronto meant I wasn’t normal; no one else had to go to Toronto. Neither of my brothers, Sal nor Leo, ever had to go to Toronto unless it was a vacation. Going to Toronto meant being away from the comfort of home and people who loved me and treated me like I was just a typical kid. It meant going to another world, where I was distinctly reminded that I was different every second of every minute I was there. Toronto also carried with it a different kind of stranger.

There, the strangers I encountered were not the same as the ones at home at the grocery store or at a red light. The hospital, ironically, was the only place strangers didn’t stare. Children didn’t really stare, and if they did it was never for long. They looked different too; I don’t
know if they looked away because they thought I was staring at them, or if it was because they knew how it felt to be stared at. The parents didn’t stare, either; they actually gave genuine smiles. The only other comfort was that almost every child at the hospital was there because they too were different. I guess being different made us the same? I wonder if they felt the same way.

It was only the doctors and their residents that stared when I was at the hospital. It was a different kind of stare. A powerful one. Not wonderment, not normal curiosity … a medical one where all they see is the patient and not the person — THAT stare. I equate that stare with the look I’m sure I have when I look at all the material I need for a project, and I think about how I’m going to turn that mess into a masterpiece. Fascinated. Challenged and calculating. In the examining rooms there were always too many sets of eyes to stare down as I sat on the examining table, and I never knew where to look. Do I look at the residents? The surgeon? My mom? The ceiling? Most of the time I would look anywhere but at a human. Sometimes I felt comfort looking in my surgeon’s eyes, so I would look at him. I now know those comforting eyes were simply experienced. He had seen so many facial abnormalities that it was normal for him to see a Treacher Collins patient. It was the entourage of resident doctors who accompanied him with their scrutinizing eyes that made the room cold and sterile.

As I continued down the freeway, I had a cocktail of emotions; I was sad for the memories of the little girl who had some unpleasant adventures to Toronto; I was laughing at other memories of her cuteness and marveling at her sassiness in the birthday and Christmas photos that also filled my mind. I was filled with warmth at how much she was truly loved. I reminded myself that I was reminiscing for a reason. Maybe all these memories came to the forefront of my mind to help me answer the questions I posed to myself about the origins of my uncomfortable feelings with certain compliments. Maybe these mental pictures and the emotions that accompanied them wanted to be recognized as an experience my child might have if they were born with Treacher Collins. A reminder to me that just as I know the happy little girl in all the other pictures, I should not forget this little girl too … because they are one and the same.

The greatest gift that you can give to others is the gift of unconditional love and acceptance.
— Brian Tracy

Fourteen years ago, in March of 2002, I received an excited call from my best friend, Melanie, reminding me that the following day was her scheduled C-section for her firstborn child. I rushed to the hospital to be there to celebrate this exciting time in her life. Her daughter weighed in at 7 lbs 6 oz. The excited first-time parents were quickly subdued when the doctors suggested that their bundle of pink joy appeared to have characteristics of Down’s syndrome. In order to rule this out, the baby needed to undergo some tests, and the results would confirm or eliminate the diagnosis. While Kiera went through the necessary testing, my dear friend was in total shock and disbelief. Her family was less than supportive and equally as frantic. Yet Melanie’s husband Tom remained rational and logical while she fell apart. The panic on Melanie’s tear-stained face and her repetitive “why me?” questions were inconsolable. She was asking questions that no one had answers to.

After a couple of hours of this “poor me” stance, I remember really wishing she would just shut up. I didn’t know what I was supposed to do or say to console her, and I was becoming increasingly frustrated because I could not empathize with her, no matter how hard I tried. My life experiences would not let me. The whole atmosphere of that hospital room, including the response from her family, struck a nerve deep within me, reaching my very core. I felt almost embarrassed. My internal reaction was strong, almost disproportionate to the situation.
as they drove to the hospital and my mom’s contractions were coming faster and closer together.

Soon after they arrived rushed to the birthing room. I was born at 2:18 p.m. with “so much hair!” Since my father still had yet to arrive, my aunt called my dad to tell him I had been born. He had decided since he had already missed the birth, he was going home to shower and shave before coming to the hospital. And then the story skipped to “the nurses loved to style your hair with barrettes” and “you were so tiny.” There was no mention of the shock or what was said and done immediately upon my arrival. There was no mention of the reactions of either my parents, or my five-year-old brother, for that matter. And for a long time that story was enough for me. I’d hear it, smile, and giggle at how much hair they said I had and carried on.

“Mom, what is it, what I’m called?” I’d asked her out of the blue one day. I was probably seven or eight years old. My mom never missed a beat. “Treacher Collins Syndrome,” she answered. That was big phrase for a little kid.

“What do all those words together mean?”

“It means that the bones in your face grew slower than the rest of your body. Your face is a little different, that’s all.”

I still recall a time where I didn’t know what she really meant by “different.” After all, I did have all the same body parts everyone else did, except my ears were a little funny, and I wore a hearing aid. But none could see them, really, because I covered them with my long hair. Her answer and my rationale made sense to me at the time.

In my teen years, as I began to realize how different I was from everyone else, I wondered what “really” happened on May 11, 1974. My
And Dad had gone home to shower first? I thought to myself. What about Dad, Mom? Did anyone prepare him? Did you call him? Did someone tell him to hurry? I mean, if they thought I was going to die, I’m sure there was more than just the amount of hair I had being talked about … But these were the questions I never asked.

“So much wrong with her ...” With those words lingering in the air, I rewind to the start of the list of things that were wrong with me. I pictured myself as the doctor that day and tried to determine what his list of “wrong” was for this baby, conjuring up a visual of my baby picture. For starters, I had no ears. In their place I had one skin tag in each spot an ear should be, making it obvious there was a hearing problem. My eyes were big and round because they were unsupported as a result of my lack of cheekbones. My mouth looked fine, but on the inside there was no palate; I had a cleft palate without a cleft lip.

I looked at my mother standing at the sink preparing our dinner as she continued with the story. I tried to imagine what her feelings were in the moments of my birth. As if she read my mind, Mom said, “The thought of losing my baby was devastating, and all I wanted was for someone to tell me that everything was going to be okay, and whatever you had was manageable. Of all the doctors that came to see you after you were born, none knew what to say. But then the following day Dr. Johnston came into the hospital room and gave me the reassurance I needed. In fact, he told us that you were going to be fine. He said you had a long road ahead of you, lots of surgeries, but you were going to be fine.

“He then told us that there was a name for what you had: Treacher Collins Syndrome. He explained that it was a rare genetic disorder, and he assured us that you were not going to die. He said you had a long road ahead of you, lots of surgeries, but you were going to be fine.”
“Your father and I did not care about the commute to Toronto, especially if it meant you were going to be cared for properly. Until your first surgery, which was your cleft, the majority of our time was spent feeding you. It took two hours to get you to drink an ounce of milk. We used those baby bottles with the little bags and the open bottoms. We would put our fingertips on the bag and press down gently so that the milk would squirt to the back of your throat so you could swallow. Not too much and just the right pressure, because we didn’t want you to choke. We had to basically bypass the palate until we got to Toronto. When we got to Toronto they fitted you with this plastic device that covered the open palate until they were able to surgically close it. After the surgery it was such a relief that you were able to take a bottle on your own.”

Reflecting on that conversation made me smile. I realized my mom was telling me about the instance where the virtue of hope and the notion that “everything is manageable” was woven into the fabric of our lives. For my mom, it stemmed from someone telling her she could handle this, and she and her daughter would be fine.

My mom’s virtues became my blessings. As I listened to her, intellectually I knew she was talking about me, but it didn’t feel like it. Instead, it sounded like she was talking about someone else’s kid—not me. I was not attached to the baby she was describing. It just seemed so far removed from who I was. As I progressed in my teen years, the types of questions became more intimate, and I was nervous to ask because I’d become more aware of her feelings. I did it anyway. “Mom, can I ask you something? When you were pregnant with me, did you smoke?”

“No, Christina, I didn’t.”

“Did you drink?”

“No, I didn’t drink.” The answers rolled off her tongue with a tone that suggested she knew that one day I would be asking these questions. Maybe she didn’t take her prenatal vitamins? She assured me that as the second child, I was planned and no risks were taken. She stated that she did everything right. “Treacher Collins was simply the result of a spontaneous genetic mutation. And genetic testing said you were a fresh mutation.”
As I read these diary entries now at this stage in my life, as a woman contemplating creating a family of my own, my view of my mother began to change. She is not only a mother but a woman. A woman who gave birth to a surprise. I spent quite some time trying to put myself in my mother’s experience all those years ago; what would it be like not to hold my daughter within moments of her birth because the doctors were trying to figure out what was “wrong” with her. She must have felt so vulnerable and scared. The societal climate in 1974 was nothing like it is today. There was no Google to assist with information or support. Social advocacy for children born with syndromes or illnesses was not something easily accessible.

As I started to see my mother as a woman and not just a mother, I wanted to ask many more personal questions like: What was it like to have your world rocked like that? Didn’t you have expectations? Didn’t you just assume your second child would be as perfect as your first … and since that expectation wasn’t met … weren’t you mad? Did you blame yourself? How about each other? Did you guys think you let each other down? Or was all that immediately sorted out and processed and you focused your attention on moving forward? Did you guys ever talk about it? Did my birth change your marriage? Strengthen it? Distance it, cause strain? I asked those questions in my head but never dared ask my mom out loud if they felt like failures. Did my parents feel that they somehow contributed to my Treacher Collins? How did they handle it? I still think, all these years later, that the syndrome plays a defining role in my relationship with both my immediate and extended family. It is an unspoken role, of course. I don’t remember talking about TCS growing up. I do remember talking about surgeries and doctor’s appointments because of it, but never talking about IT. Never talking about how IT affected me or them on emotional or mental level. And never was it a family discussion.

I am blessed through and through to have been born into such an encouraging and supportive extended family. With hindsight, I realize that we never, ever talked about feelings. No one ever admitted to being scared, no one made it “okay” to be afraid. No one labelled a feeling as sad or confusing. But we did a fine job of expressing anger and joy. Anger was an acceptable emotion, and we expressed it by yelling and blamed it on our European background.

Feelings, especially those deemed “weak” or that made others feel uncomfortable, were taboo. The message was clear that we could talk about many things: where to travel for vacation, what presents to buy, and who to invite for Sunday dinner. We certainly could have opinions, express thoughts, and yell “passionately,” but we could not discuss fear or confusion.

I got that unspoken message loud and clear at a young age. There was always a lot of deafening silence. It’s fascinating how unspoken words translate somehow into prescribed roles in a family. Everyone knows their place without it ever being assigned. Recalling these memories of my childhood, I cannot help but marvel at the instinctive way a child can read a room and be able to conduct themselves in their role accordingly. I was too young to know on a conscious level the notion, “I can’t let them see me cry,” but somehow I subconsciously knew.

My role was to be special and strong. My extended family continuously talked about how brave I was, how strong I was, and how inspiring I was. On the eve of the day before we were to leave for surgery, my aunts and uncles would stop by for a visit to say goodbye. It was a bittersweet visit because I loved playing with my cousins and being surrounded by people that loved me. But on those particular visits, there was worry camouflaged by repetition of “everything is going to be fine” among the adults. Inevitably, someone would say, “So, Chrissy, are you ready for tomorrow?”

“I’m fine. It’s no big deal.” I would shrug it off like water rolling off my back; it was all part of the script.

“Of course you’re fine, you’re strong. You’re an old pro at this,” my Zia Margaret would say as she pulled me up on her lap. I’d suck back
tears and fake a smile. After a few minutes, just as I began to feel my throat closing as it does before I start to cry, I would wiggle down off her lap and make my way out of the room. I’d coach myself, I’m strong, strong doesn’t cry.

In my pre-teen years I’d purposefully try to avoid the visitors by being heavily involved in playing with a toy or a game and refusing to be torn away to sit and chat. I was hoping they would just forget I was there and keep talking to my parents. Inevitably my mom or dad would holler for me to come upstairs for a minute to see whoever was visiting because “they came to see you, Chris!” I would make a game out of it, challenging myself to see how long I could stay in the dining room with everyone there the night before a surgery, enduring their questions and superficial assurance that everything would be fine and this was no big deal. I would listen to what they said until the uncomfortable was too much to stomach, and I would excuse myself.

I soon realized that it didn’t matter how many times I chanted “don’t cry, don’t cry, don’t cry, don’t listen, stop listening, and don’t cry” silently in my head. My eyes still stung, and before anyone could notice—or if they did, they pretended they didn’t—I bolted out of the room. The bathroom was always my safe haven, the safest room in the house to be alone with sadness. When the bathroom door was closed, no one disturbed you. The door locked too, but more importantly, when you turned the water on, no one could hear you cry.

As I got older and it was no longer appropriate to be sitting on anyone’s lap or wait to be summoned upstairs to greet the visitors, I was stuck. I could not leave the room without it being obvious that I was uncomfortable. When I could no longer slink out of the room, I would just nod, smile, and change my game plan to digging my nails into my hands to distract myself by inflicting pain on another part of my body and focus my attention there, instead of what was happening around me. Ironically, I still use this form of self-harm to get through difficult situations. Pain brings you into the present. It forces the attention away from the panic and onto my physical pain. Was it distraction or control? During these dreaded encounters, the voice in my head screams at the innocent person highlighting this perceived bravery of mine: Please don’t patronize me. I know you mean well, but still, it does nothing to curb my innate desire to scratch your eyes out! It wasn’t until I was in my early twenties, and just a little bit more aware of myself, my Treacher Collins, and my family dynamics, that I finally could muster up the courage to go against the answer they were expecting.

Instead, I began saying, “Actually, you never get used to it. I’m excited about what the outcome will look like, but it’s always nerve-wracking and scary.”

I just wished I could have said it without my voice cracking. When I gave that kind of response, it usually left others speechless, and they would simply agree with me or smile and say nothing. I felt a sense of triumph when my voice could silence the room. This was exactly what the situation called for; the “right thing” to say in these situations, or at least what I wanted to hear, was silence. Revealing feelings does not diminish one’s strength. Quite the contrary, time has taught me.

Obviously there was always something that needed to be said; social etiquette dictates such. I just wished they could have empathized: “I can only imagine how nervous/scared you must feel… I’ll be thinking about you the whole time.” Something like that.

When I watch family films of my brothers and I am reminded of all the wonderful memories we have; we truly were a happy bunch. For five years, it was just me and Sal. He was my first friend, and he took his role of big brother seriously. He was very doting and affectionate and kind. Family films capture his kindness when he would pull me up the hill in sleds and ride with me downhill. He would take me on bike rides around the neighbourhood. I remember a time when we were having a great time just racing around on our bikes in front of our house when this unknown neighbourhood kid suddenly began riding his bike on the opposite side of the road, in the opposite direction of me. It was quite obvious that he did this in order to look at me. He did the same thing when I turned around on my bike. No matter what direction I turned, he was
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