

*“It’s Chyckxn!”*



# *“It’s Chyckxn!”*

The Unculinary Way  
I Made Life Palatable



A Memoir

*Christina Stramacchia*



*Stramacchia Books*

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

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*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.*



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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## Prologue



“*M*om, 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.

*Hmmm ... 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!*



*Dad, my brother and I.*



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



*Seven year old me.*

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 made sense in my mind that a person with a black eye or a cast over their nose would warrant a stare. 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



their parenting? I could see the fake “play” parents would do in the checkout line with their child sitting in the grocery cart. The parent would realize who their child was staring at and immediately attempt to distract the child, sometimes trying to engage them in a conversation, other times physically redirecting their head. If that didn’t work, they’d try initiating a game until it was their turn at the cashier. The kid would try to dodge their head around their now-blocked view, and I would see them look up at their parent with a puzzled expression that said, “Now you want to play with me? But I’m trying to figure out what’s wrong with the girl behind you!” Tough choice to make: play with my now-engaged parent or figure out what’s up with that lady behind them. Feeling as uncomfortable as the parent, I would grab a rag magazine off the rack and read an article just to ease the tension for *them*. I think of those times now and can’t believe I did that—compromising *myself* so *someone else* wouldn’t feel embarrassed.

Fast forward twenty years, and the “It’s Chyckxn” analogy of pretending something did not exist when in reality it did. My parents adopted this coping technique on a larger scale; they would only tell me what they needed to in order to guide me through whatever Treacher Collins challenge presented itself. Let’s pretend we are having chicken for dinner when, in fact, it’s some other type of meat. Let’s pretend that the emotional impact of having TC doesn’t affect the person that it afflicts when, in fact, it does. Treacher Collins isn’t really there and that it doesn’t affect the person it afflicts when, in fact, it does.

It’s Chyckxn. Get it?

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*

“*W*hy 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

ager resents us and wants to know "Why would you guys have a kid knowing you were passing on Treacher Collins?"

As I silently applauded myself—*oh my God, I did it, I voiced my fear out loud like verbal diarrhea!*—I secretly hoped he didn't ask me to repeat myself in order to buy himself more time to come up with a response. Thankfully, he didn't.

Nick was silent for a few minutes while he processed what I had said. He sat there, holding his head with one hand and tracing his top lip with his tongue, which was a clear indication that he was in deep thought. I knew his habits well.

He did not shame, chastise, or brush off what I said with superficial words of uncomfortable encouragement. Nick did not do that. I didn't expect it, because it wasn't his style. He had always been a little rough around the edges and never one for sugar-coating. I loved and hated that about him.

When he finally did speak, he simply said, "I don't know, Pie. I don't know what the right answer is. I don't think a child is going to hate you, or us for that matter. You are going to be a great mom. You are going to be able to get them through things because you've already been there. It's a chance I guess we are going to have to take. The kid could hate us for all kinds of other things too. I'm sure we will mess them up in other ways, and we won't even know it!"

What came next was right out of left field. "Pie, do you blame your parents?"

"It's different!" I responded defensively. "They didn't KNOW. Knowingly doing something is deliberate. It's a game-changer."

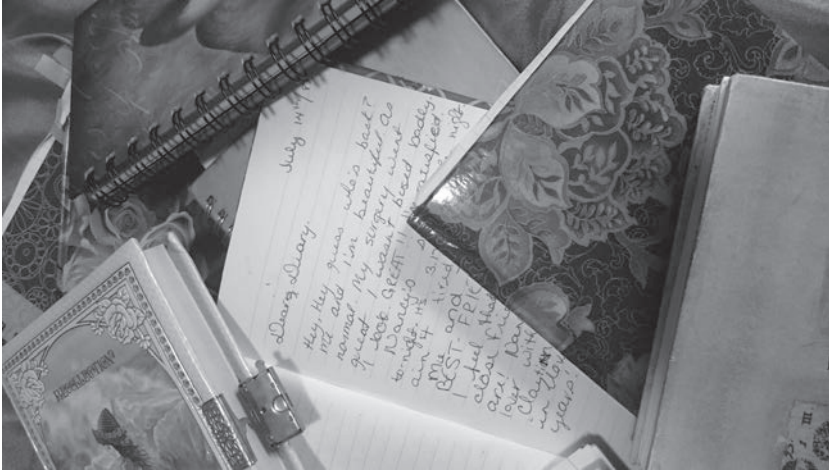
He pressed on. "If you found out they knew ... just pretend they knew and had you anyway, how would you feel?"

I stared at him. That was a hard question. "I know I would want to know what their thought process was, what they told each other during that conversation, and what the overwhelming evidence was that supported going ahead with the decision. Did they ever consider I would ask them about their decision? and what was the deciding factor that made them decided to go ahead with a pregnancy?" I didn't give him a straight answer, and I knew it.



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



no particular order, pondering memories and putting myself “there again,” remembering all the feelings I wrote about, remembering the person I was. Oh the things I would tell my seven-, fifteen-, and twenty-year-old self now ...

There was no way for my mother to know all those years ago that her simple idea of a diary would be one of her greatest gifts to me. There was no way for me to know at the time I was writing in the diaries that I would be coming back to them years later to find the answer to one of the most important questions of my life.

In the days that followed I spent some quiet time sipping lattes on the couch, reading, remembering my naïveté and innocence, along with my heartaches and accomplishments. I could see where many of my attributes were born.

The chapters that follow in this memoir are excerpts of pivotal life moments and lessons I’ve taken from my diaries that drew me closer to our decision to create a family of our own.

## Acknowledgements



*T*his memoir would not have been possible if not for Mom and Dad's fierce devotion to ensuring I had an ordinary life. I am grateful for my mother's unwavering faith in her little girl with Muppet ears and a tiny jaw, that, unbeknownst to her, watered the seeds of resilience and a determination that has enriched my life beyond what this simple thank-you can convey; my father for capturing my childhood photos and videos like only a proud father can; both of my brothers, for all the lessons you've taught me (both intentional and not) about friendships and the importance of having people you can count on to be in your corner.

My life has taught me that "it takes a village to raise a child," and this memoir is evidence of that. In addition to my "village" of aunts, uncles and cousins, a special thank you to Marisa Spadafora-Lipari and Lisa Smiatacz; without their relentlessness, this memoir would still sit unfinished and unwritten.

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